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Delivering Diabetes Care to Ethnic Diversity
(DEDICATED): Exploring potential barriers and solutions
to delivering high quality diabetes care to people from ethnic
minority groups

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TABLE OF CONTENTS

TABLE OF CONTENTS.....	i
GLOSSARY OF ACRONYMS	ix
LIST OF TABLES	xii
LIST OF FIGURES	xiii
ACKNOWLEDGMENTS	xiv
DECLARATION.....	xvi
ABSTRACT	xvii
CHAPTER ONE.....	- 1 -
INTRODUCTION TO THE THESIS	- 1 -
1.1. Introduction	- 1 -
1.2. Definitions of Key terms.....	- 2 -
1.3. Diabetes health inequalities.....	- 5 -
1.4. Background to the clinical/scientific problem and justification for the research.....	- 9 -
1.4.1. The UK national picture, impact and diabetes prevalence	- 9 -
1.4.2. The choice of Coventry for the study	- 12 -
1.5. Diabetes self-management support in ethnic minority groups	- 14 -
1.6. The researcher and motivation for the research topic	- 19 -
1.7. Naming and launching of the project.....	- 21 -
1.8. Previous literature and systematic reviews	- 24 -
1.9. Proposed research design and methodological approaches	- 27 -
1.9.1. Proposed research questions/aims/objectives.....	- 27 -
1.9.2. Study design / investigation plan	- 27 -
1.10. Importance of answering the proposed research questions to the NHS.....	- 28 -
1.11. Chronology of the research / Outline of chapters	- 29 -
CHAPTER TWO.....	- 32 -
CULTURAL BARRIERS IMPEDING ETHNIC MINORITY GROUPS FROM ACCESSING EFFECTIVE DIABETES CARE SERVICES: A SYSTEMATIC REVIEW OF OBSERVATIONAL STUDIES.....	- 32 -
2.0. Abstract	- 32 -
2.1. Introduction	- 33 -
2.2. Methods	- 35 -
2.2.1. Data sources, search strategy and eligibility.....	- 35 -
2.2.2. Inclusion criteria.....	- 35 -
2.2.3. Selection criteria	- 37 -

2.2.4. Data extraction and quality assessment of studies	37 -
2.2.5. Data analysis.....	38 -
2.3. Results	38 -
2.3.1. Available evidence.....	38 -
2.3.2. Characteristics of included studies.....	40 -
2.3.3. Quality assessment of included studies and risk of bias.....	41 -
2.3.4. Cultural barriers to diabetes care and management	53 -
2.3.4.1. Cultural adherence to diet, exercise, and social interactions.....	53 -
2.3.4.2. Commitment to religious beliefs.....	55 -
2.3.4.3. Linguistic differences between patients and health workers	56 -
2.3.4.4. Low health literacy levels	57 -
2.3.4.5. Beliefs about health and illness	58 -
2.3.4.5.1. Causation.....	58 -
2.3.4.5.2. Integrating curative and diabetes self-management measures into everyday life	60 -
2.3.4.6. Belief in expert and professional support.....	61 -
2.3.4.7. Low accessibility of culturally appropriate services and information.....	62 -
2.3.4.8. Low concordance with Western professional advice	63 -
2.4. Discussion.....	64 -
2.4.1. Discussion of key findings	64 -
2.4.2. Strengths and limitations of the review	66 -
2.4.3. Conclusions, implications for practice and recommendations for further research.....	67 -
CHAPTER THREE	70 -
THE IMPACT OF CULTURALLY-COMPETENT DIABETES CARE INTERVENTIONS FOR IMPROVING DIABETES-RELATED OUTCOMES IN ETHNIC MINORITY GROUPS: A SYSTEMATIC REVIEW.....	70 -
3.0. Abstract	70 -
3.1. Introduction	71 -
3.2. Methods	72 -
3.2.1. Eligibility	72 -
3.2.2. Search strategy.....	73 -
3.2.3. Selection criteria	74 -
3.2.4. Development of a culturally-competent assessment tool for assessing health interventions....	77 -
3.2.5. Data extraction and quality assessment of studies	83 -
3.3. Results	83 -
3.3.1. Available evidence and data analysis.....	83 -

3.3.2. Characteristics of studies	- 83 -
3.3.3. Risk of bias.....	- 90 -
3.3.4. Cultural competence of interventions	94
3.3.5. Development and types of interventions	96
3.3.6. Components and delivering of interventions	96
3.3.7. Training to deliver culturally-competent interventions.....	98
3.3.8. Diabetes-related outcome measures.....	99
3.3.9. Impact on clinical outcomes.....	99
3.3.10. Impact on knowledge, attitude change and self-efficacy	100
3.3.11. Evaluation of cost effectiveness.....	101
3.4. Discussion.....	102
3.4.1. Statement of main findings.....	102
3.4.2. Strengths and limitations	102
3.4.3. Findings in relation to other studies	104
3.4.3.1. Communication	105
3.5. Conclusion and recommendations for future research	105
CHAPTER FOUR.....	107
METHODOLOGY FOR THE RESEARCH.....	107
4.1. Introduction	107
4.2. Quantitative and qualitative research methodologies: Definitions, differences, historical evolution and application in health sciences	108
4.3. Quantitative and Qualitative Research Paradigms	112
4.4. Mixed methods (MM)	115
4.5. Historical evolution of mixed methods.....	117
4.6. Pragmatic paradigm worldviews.....	120
4.7. Morgan’s Pragmatic Framework Approach to Methodology in Social Sciences	121
4.8. Strengths and limitations of the pragmatist paradigm	124
4.9. Justifications for using pragmatic methodology	126
4.10. Data analysis of the research study	131
4.11. Chapter summary.....	132
CHAPTER FIVE.....	133
DELIVERING DIABETES CARE TO ETHNIC MINORITY POPULATIONS - A SINGLE CITY CASE STUDY	133
5.0. Abstract	133
5.1. Introduction	134

5.2. Research design and methods	136
5.2.1. Survey design	136
5.2.2. Population and data collection	142
5.2.3. Data analysis.....	142
5.3. Results	143
5.3.1. Response rate.....	143
5.3.2. Characteristics of participating general practices	145
5.3.3. Diabetes prevalence by ethnicity.....	148
5.3.4. Staff self-reported culturally-competent diabetes services and their knowledge about local services to ethnic minority groups.....	150
5.3.5. Staff self-reported barriers and utilisation of diabetes annual checks	154
5.3.6. Employed ethnic minority staff.....	156
5.3.7. Staff training and diabetes knowledge	162 -
5.4. Discussion.....	162 -
5.4.1. Discussion of the principal findings.....	162 -
5.4.2. Strengths and limitations	167 -
5.5. Conclusion and recommendations for future research	168 -
CHAPTER SIX.....	170 -
DESIGNING AN EFFECTIVE CULTURALLY-COMPETENT DIABETES CARE SERVICE IN PRIMARY CARE: A PARTICIPATORY RESEARCH STUDY TO IMPLEMENT EVIDENCE.....	170 -
6.0. Abstract	170 -
6.1. Introduction	171 -
6.2. Research aim/objectives	172 -
6.3. Participatory research methodology, selection and justification	172 -
6.4. Research methods.....	176 -
6.4.1. Study design and methods.....	176 -
6.4.2. Research settings	177 -
6.4.3. General practice recruitment and inclusion criteria	177 -
6.4.4. Difficulties in recruiting general practices.....	178 -
6.4.5. Withdrawal of general practice.....	179 -
6.4.6. Participant recruitment.....	180 -
6.4.7. Protection of Human Participants Measures: Ethical Considerations and Confidentiality	181 -
6.4.8. Developing and building relationships and trust	184 -
6.4.9. Preparing for participatory research and retaining participants	186 -
6.4.10. Participatory research approach.....	186 -

6.4.11. Data collection methods	- 188 -
6.4.11.1. Participant observations as a data collection tool.....	- 188 -
6.4.11.2. Participatory research group meetings.....	- 190 -
6.4.11.3. Semi-structured face-to-face interviews and undertaking participants' interviews ..	- 191 -
6.4.12. Data management.....	- 195 -
6.4.12.1. Use of recording instrument.....	- 195 -
6.4.12.2. Use of fieldnotes	- 195 -
6.4.12.3. Transcription of participatory research group meetings and interviews	- 196 -
6.4.13. Data analysis and presentation.....	- 197 -
6.4.13.1. Use of Computer Package: NVivo 9.2 package	- 197 -
6.4.14. Reliability and validity of the data.....	- 199 -
6.5. Results	- 201 -
6.5.1. Description of the participating general practice	- 201 -
6.5.2. Chronology of the research.....	- 202 -
6.5.2.1. Participant observations	- 202 -
6.5.2.2. Participatory group meetings.....	- 205 -
6.5.2.2.1. Participatory meeting attendance rates	- 206 -
6.5.2.2.2. Characteristics of participants.....	- 206 -
6.5.2.2.3. Chronology of the participatory research group meetings.....	- 210 -
6.5.2.2.4. Participatory Research Meeting One	- 215 -
6.5.2.2.5. Participatory Research Meeting Two	- 218 -
6.5.2.2.6. Participatory Research Meeting Three	- 219 -
6.5.2.2.7. Participatory Research Meeting Four	- 219 -
6.5.2.2.8. Participatory Research Meeting Five	- 221 -
6.5.2.3. Semi-structured face-to-face interviews with practice staff and patients	- 222 -
6.5.2.4. Semi-structured interviews with Multilingual Link Workers (MLWs)	- 223 -
6.5.3. Synthesis on of the results based on emerging themes	- 224 -
6.5.3.1. Need for the MLW service (cultural barriers)	- 226 -
6.5.3.1.1. Cultural differences/barriers.....	- 226 -
6.5.3.1.2. Low health literacy level.....	- 229 -
6.5.3.1.3. Language barriers (problems associated with family members as interpreters) ..	- 230 -
6.5.3.1.4. Commitment to religion.....	- 233 -
6.5.3.2. Training and education	- 234 -
6.5.3.2.1. Training of practice staff	- 235 -

6.5.3.2.2. Training of MLW and level of specialist knowledge (training of trainee)	236 -
6.5.3.2.3. Trainee-patient training	238 -
6.5.3.2.4. Supervision and monitoring training.....	239 -
6.5.3.3. Functions of DSMLW	239 -
6.5.3.3.1. Patient referral pathway of DSMLW service	240 -
6.5.3.3.2. Responsibilities of DSMLW.....	242 -
6.5.3.3.3. Diabetes self-help groups.....	250 -
6.5.3.4. Information sharing.....	250 -
6.5.3.4.1. Professional information sharing between DSMLW and staff.....	251 -
6.5.3.4.2. Information sharing with patients by DSMLW	251 -
6.5.3.4.3. Education sessions/clinical consultations	252 -
6.5.3.5. Partnership working.....	254 -
6.5.3.5.1. Working relationship within the general practice	254 -
6.5.3.5.2. Working relationship with partner agencies.....	255 -
6.5.3.6. Service commissioning and challenges	257 -
6.5.3.6.1. Sustainability and financial implications (managing present and future diabetes service provision)	257 -
6.5.3.6.2. Engaging and sharing good practice	259 -
6.6. Discussion.....	261 -
6.6.1. Discussion of key findings	261 -
6.6.2. Strengths and limitations	263 -
6.7. Conclusions/recommendations	265 -
CHAPTER SEVEN	268 -
DISCUSSION OF RESEARCH FINDINGS: SYNTHESIS OF RESEARCH EVIDENCE.....	268 -
7.1. Introduction	268 -
7.2. Part One	269 -
7.2.1. Statement of principal findings	269 -
7.2.2. Discussion of principal findings arising from the research	270 -
7.2.2.1. Continuing cultural barriers to effective diabetes care services.....	271 -
7.2.2.2. Benefits of culturally-competent diabetes interventions	275 -
7.2.2.3. Diabetes prevalence amongst ethnic minority groups in Coventry (1:3)	280 -
7.2.2.4. Good rates of general practices reporting of patients' ethnicity.....	281 -
7.2.2.5. Lack of structured education programmes in Coventry	284 -
7.2.2.6. Diabetes Specialist Multilingual Link Worker service framework.....	288 -

7.3. Part Two	- 294 -
7.3.1. Practicalities of the research process.....	- 294 -
7.3.2. Planned research vs. completed research	- 294 -
7.3.3. Lessons learned and what this researcher would do differently	- 298 -
7.3.4. Reflection	- 301 -
7.3.5. Key strengths and weaknesses of the methodology and design of the study.....	- 301 -
7.3.6. Contextual and other methodological strengths and limitations	- 303 -
7.3.6.1. Contextual limitations and strengths.....	- 303 -
7.3.6.2. Inclusion of all ethnic minority groups and all types of diabetes	- 305 -
7.3.6.3. Use of mixed methodology as a pragmatic approach.....	- 305 -
7.3.6.4. The researcher	- 307 -
7.3.6.4.1. Cultural awareness:.....	- 308 -
7.3.6.4.2. Cultural knowledge:	- 309 -
7.3.6.4.3. Cultural sensitivity:.....	- 309 -
7.3.6.4.4. Cultural competence:.....	- 309 -
7.3.6.5. Interview transcripts	- 310 -
7.3.6.6. Designing the general practice survey	- 311 -
7.3.6.7. Participatory research recruitment difficulties	- 311 -
7.4. Part Three.....	- 311 -
7.4.1. Further implications of the research.....	- 312 -
7.4.2. Implications for practice.....	- 313 -
7.4.3. Research outputs	- 315 -
7.5. Chapter summary.....	- 317 -
CHAPTER EIGHT	- 320 -
CONCLUSIONS AND THE WAY FORWARD.....	- 320 -
8.1. Summary of the main findings	- 320 -
8.2. Implications of the research and recommendations for implementation.....	- 322 -
8.3. Conclusions	- 324 -
REFERENCE LIST.....	- 326 -
APPENDICES	- 353 -
Appendix 1: A pilot general practice survey.....	- 353 -
Appendix 2: DEDICTED project launch invitation letter and programme	- 360 -
Appendix 3: The impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups: A systematic review	- 361 -

Appendix 4: Cultural barrier systematic review data extraction form.....	- 377 -
Appendix 5: Culturally-competent care interventions data extraction form	- 379 -
Appendix 6: National Research Ethics Service (NRES) ethical approval.....	- 382 -
Appendix 7: Letter to GP Surgery about the General Practice Survey.....	- 385 -
Appendix 8: Invitation letter to case study practices for participatory research	- 387 -
Appendix 9: Invitation letter to staff participants about the PR meetings	- 388 -
Appendix 10: Participant Information Sheet for staff taking part in the research.....	- 391 -
Appendix 11: Invitation letter to patient about the implementation meetings.....	- 395 -
Appendix 12: Invitation letter about the study to ethnic minority patients to be sent out by GP surgery.....	- 396 -
Appendix 13: Participant Information Sheet for patients taking part in the research	- 397 -
Appendix 14: Written contract between University of Warwick and participating practices	- 401 -
Appendix 15: Patient Consent Form	- 411 -
Appendix 16: Staff Consent Form.....	- 412 -
Appendix 17: Notice Patients.....	- 413 -
Appendix 18: Topics for discussion at face-to-face interviews with ethnic minority patients	- 414 -
Appendix 19: Draft topics for discussion at face-to-face interviews with general practice staff ..	- 416 -
Appendix 19A: Topics for discussion at face-to-face interviews with staff.....	- 418 -
Appendix 20: DSMLW Job Description proposed by Admin Staff 1.....	- 420 -
Appendix 21: Generic Job Description for Multilingual Link Worker	- 421 -
Appendix 22: Request to PR group meeting participants to validate DSMLW Job Description.....	- 424 -
Appendix 23: List of conference /seminar presentations arising from DEDICATED study so far (n=27)	- 426 -

GLOSSARY OF ACRONYMS

Acronyms	Name in full
AAs	African-Americans
AC	African-Caribbean
ADA	American Diabetes Association
ALWs	Asian link workers
BERTIE	Bournemouth Type 1 Intensive Education Programme
BME	Black and Minority Ethnic
BMI	Body Mass Index
BP	Blood Pressure
CASP	Critical Appraisal Skills Programme
CCAT	Culturally-Competent Assessment Tool
CCGs	Clinical commissioning groups
CI	Chief Investigator
CVD	Cardiovascular diseases
DAFNE	Dose Adjustment For Normal Eating
DEDICATED	Delivering Diabetes Care to Ethnic Diversity
DESMOND	Diabetes Education and Self-Management in Ongoing and Newly Diagnosed
DH	Department of Health
DM	Diabetes Mellitus
DSME	Diabetes Self-Management Education
DSMLW	Diabetes Specialist Multilingual Link Worker
DSNs	Diabetes specialist nurses

EMGs	Ethnic Minority Groups
GCP	Good Clinical Practice
GP	General Practitioner
HbA1c	Glycosylated Haemoglobin
HCPs	Health care professionals
HDL	High-Density Lipoprotein
HV	Health visitor
ICH	International Conference on Harmonisation
IDF	International Diabetes Federation
ITT	Intention to treat
MDT	Multidisciplinary team
MeSH	Medical Subject Headings
MLW	Multilingual Link Worker
MM	Mixed methods
NCCC	National Collaborating Centre for Chronic Conditions
NIHR	National Institute for Health Research
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence (formerly known as National Institute for Clinical Excellence)
OHAs	Oral hypoglycaemic agents
OPD	Outpatients Department
PC	Primary Care
PCT	Primary Care Trust
PMS	Personal Medical Service

PR	Participatory research
PRISMA	The Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QALY	Quality Adjusted Life Years
QOF	Quality and Outcomes Framework
QOL	Quality of Life
RCT	Randomised Controlled Trial
RD	Registered dietitian
SAs	South Asians
SHAs	Strategic Health Authorities
SMBG	Self-Monitoring of Blood Glucose
SMS	Self-management support
SR	Systematic Review
T1DM	Type 1 Diabetes Mellitus
T2DM	Type 2 Diabetes Mellitus
UHCW NHS Trust	University Hospitals Coventry and Warwickshire NHS Trust
UK	United Kingdom
UKADS	United Kingdom Asian Diabetes Study
WHO	World Health Organisation
WISDEM	Warwickshire Institute for Diabetes, Endocrinology and Metabolism
WMS	Warwick Medical School

LIST OF TABLES

Table 2.1: Search Strategy.....	- 36 -
Table 2.2: Summary of included studies	- 42 -
Table 2.3: Ethnicity of ethnic minority groups.....	- 49 -
Table 2.4: Quality assessment for included qualitative research studies (Popay <i>et al.</i> , 1998).....	- 50 -
Table 2.5: Quality assessment for included quantitative studies (Jadad <i>et al.</i> , 1996).....	- 51 -
Table 2.6: Criteria for reporting and assessing mixed methods research (Creswell & Plano Clark, 2007). -	52 -
Table 3.1: Search strategy	- 74 -
Table 3.2: Culturally-Competent Assessment Tool (CCAT) for Healthcare Interventions in EMGs	- 80 -
Table 3.3: Studies included in the review	- 85 -
Table 3.4: Risk of bias assessments in experimental studies [RCTs + quasi experimental studies [From Moher <i>et al.</i> (2010)]]	- 91 -
Table 3.5: Quality assessment for included qualitative and action research studies (Popay <i>et al.</i> , 1998). -	92 -
Table 3.6: Quality assessment for included retrospective cohort studies (Critical Appraisal Skills Programme, 2006)	- 93 -
Table 3.7: Culturally-competent assessment of included studies based on a novel devised tool titled: Culturally-Competent Assessment Tool (CCAT) for Healthcare Interventions in ethnic minority groups by these research authors	95
Table 4.1: Elements of quantitative and qualitative research in the process of research adapted from Creswell and Plano Clark (2007:29)	112
Table 4.2: Comparative differences between quantitative and qualitative researchers: adapted from Neuman (2006) and Gall, Borg & Gall (1996) in Manning and McMurray (2010:10).	114
Table 4.3: Selected writers important in the development of mixed methods research and their contributions, adapted from (Creswell and Plano Clark, 2007:14).....	118
Table 4.4: A Pragmatic Alternative to the Key Issues in Social Science Research Methodology (adapted from Morgan 2007:71).....	124
Table 5.1: The General Practice Service Survey on EMGs with diabetes.....	138
Table 5.2: Spread of patients in general practices.....	149
Table 5.3: Distribution comparison of different patients with diabetes	150
Table 5.4: Staff self-reported barriers impeding delivering of effective diabetes services to EMGs	154
Table 5.5: The spread of staffing in general practices	157
Table 5.6: Assessment of culturally-competence level of general practices using the tool proposed by Zeh <i>et al.</i> (2012)	157
Table 6.1: Participatory research meeting (PRM) attendance rates.....	- 206 -
Table 6.2: Characteristics of participants (n=9) in both PR group meetings and one-to-one interviews. -	207 -
Table 6.3: Chronology of the participatory research meetings	- 211 -
Table 6.4: Themes and subthemes	- 225 -
Table 6.5: Language spoken by patients within the general practice.....	- 230 -
Table 6.6: Recommended in-house training and skills for DSMLW	- 237 -
Table 6.7: Recommended external training and skills for DSMLW	- 238 -
Table 6.8: Recommended specialist skills and training of DS MLW.....	- 238 -
Table 6.9: Diabetes Specialist Multilingual Link Worker Job Description	- 243 -

LIST OF FIGURES

Figure 1.1: Photo of speakers and sponsors at the launch event	- 24 -
Figure 2.1: Flow chart (adapted from Moher et al. (2009) PRISMA) for screening and included studies on cultural barriers impeding ethnic minority groups from accessing effective diabetes care services.....	- 39 -
Figure 3.1: Flow chart (adapted from Moher <i>et al.</i> (2009) PRISMA) of screening and included studies ...	- 76 -
Figure 4.1: Flow diagram of the thesis methodological approaches	131
Figure 5.1: Flow chart showing the participation of general practices in the survey	144
Figure 5.2: Summary of the characteristics of participating general practices	146
Figure 5.3: Patients-to-GP and patients-to-total staff ratios in participating general practices	147
Figure 5.4: Comparison of the prevalence of diabetes in non EMGs and EMGs	149
Figure 5.5: Staff self-reported culturally-competent diabetes services provided to EMGs	151
Figure 5.6: Local services stated by staff perceived would support practices to deliver better services to EMGs with diabetes	153
Figure 5.7: Comparison of DNA rates in diabetes annual checks in majority and minority groups	156
Figure 5.8: Full time and part time staff per general practice	157
Figure 6.1: Flow diagram for the proposed Diabetes Specialist Multilingual Link Worker framework model (based on PR meeting group discussions and one-to-one-face interviews).....	- 241 -

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DECLARATION

I declare that none of this work has been submitted for a degree at another university.

The preparation of this thesis manuscript was entirely my own work, but I have benefitted from the comments and suggestions of my supervisors on earlier drafts.

The two systematic literature reviews described in Chapters Two and Three were collaborative piece of research that I led. Inclusion and exclusion decisions were shared between myself and my supervisors. I analysed the included papers using thematic analysis.

The General Practice survey (Chapter Five) questions were adopted from a previous pilot survey by myself (Zeh, 2010), then reviewed by supervisors and lay patient user group, all described within the respective chapter's methods.

The topic guides for the interviews with participants (Chapter Six) were informed by earlier literature and through discussion with my supervisors. The topics of participatory research meetings (Chapter Six) arose during group discussions with research participants and were also informed by earlier literature. I recruited the participants, conducted the interviews, arranged for transcription of the audio-taped data, and carried out the thematic analysis myself.

Publications

One publication (Zeh, 2010) describes preparatory work and ideas relevant to this research but was published before I registered for the PhD study. Two publications arise directly from the PhD research and were published before thesis submission (Chapter Three); one paper presented in Chapter Two, is in press. The two publications are indicated within the respective chapters, referenced throughout the work and also included as appendices.

ABSTRACT

Background/Aim

Diabetes is a chronic metabolic condition with worldwide prevalence and burden increasing rapidly, particularly in ethnic minority groups (EMGs). Health inequalities and inadequate provision of diabetes care services to EMGs are recognised, primarily because EMGs express a strong cultural element in healthcare and some healthcare professionals lack sufficient cultural competence. The primary aim of this research was therefore to develop an in-depth understanding of cultural barriers within diabetes services and recommend how services can be tailored to meet the needs of EMGs with diabetes in a medium-sized UK ethnically mixed city.

Methods

Two systematic reviews were completed. Primary data were collected using mixed methods: a General Practice survey, participatory case study and interviews with ethnic minority patients and health workers. These were analysed using descriptive statistics and thematic comparisons.

Results

The findings showed cultural barriers to the uptake of diabetes services across global multi-ethnic populations and some effective interventions. The first systematic review on cultural barriers in accessing effective diabetes care services, included 22 heterogeneous studies and identified eight cultural barriers, perceived by EMGs as compromising their care. The second review elucidated approaches to overcome or minimise these barriers by investigating the impact of culturally-competent interventions from 11 experimental studies. Using a novel culturally competent assessment tool (CCAT) to assess existing interventions, it was found that any structured intervention, tailored to EMGs by integrating elements of culture, language, religion, and health literacy skills, produced a positive impact on important patient outcomes.

In the Population General Practice survey, one in three people with diabetes from the diabetic population compared with one in five staff were from EMGs. Ninety-four per cent of General Practices reported the ethnicity of their populations. Improved number of diabetes annual checks was seen in the majority white British population compared to EMGs. Key cultural barriers included language and strong traditions around food, coupled with less culturally competent providers. Cultural issues were further explored in one participatory research General Practice case study. This practice selected and prioritised the designing of a Diabetes Specialist Multilingual Link Worker (DSMLW) model, aimed at bridging the inequality gaps in diabetes primary care service provision.

Conclusions/recommendations

This research proposes that future culturally-competent interventions should be structured, including elements of culture, language, religion and health literacy skills, tailored to the individual ethnic minority population. These components should be assessed to ensure they meet the needs of specific EMGs. In the absence of linguistically and/or culturally-competent staff, a DSMLW Service framework may support primary care. Future studies and clinical audits involving EMGs, are warranted.

CHAPTER ONE

INTRODUCTION TO THE THESIS

If you talk to a man in a language he understands, that goes to his head. If you talk to him in his language, that goes to his heart.

--Nelson Mandela--

1.1. Introduction

Diabetes prevalence worldwide is increasing rapidly, especially in ethnic minority groups (EMGs) who are particularly susceptible to the disease, presenting substantial challenges to the individual and society. It is a lifelong disease, which causes serious health problems, enormous suffering, permanent disability and untimely death, with EMGs often experiencing poorer health outcomes (Johnson *et al.*, 2000; Oldroyd *et al.*, 2005; Roberts, 2007).

This introductory chapter of the PhD thesis highlights the health inequalities in diabetes service provision by examining the clinical problem and the size and impact of diabetes mellitus (DM) in ethnic minority populations in the UK. The chapter also sets out the reasons for choosing Coventry as the investigation site for the primary research data collection, including the researcher's motivation in the topic. It further explores diabetes self-management, particularly in EMGs, and the literature that informed the research questions. The chapter concludes with the primary research question, the aim and objectives and a summary of the research methodology as well as the importance of the research to the National Health Service (NHS). The literature suggests that much still needs to be understood and researched in this area of health. The chronology of the

chapters is signposted, including the contribution of this research project to the existing body of knowledge in this area.

1.2. Definitions of Key terms

Diabetes: Shortened version for diabetes mellitus, a condition where the body fails to properly utilise the ingested glucose from food. This could be due to lack of the hormone insulin or because the available insulin produced by the pancreas is not working effectively. When a person has diabetes, the glucose needed for energy is not absorbed by the body efficiently, leading to elevated glucose levels (hyperglycaemia) which can damage body tissues and over time cause long-term complications. Diabetes mellitus comes from the Greek word '*diabetes*' meaning '*siphon*' - to pass through, and the Latin word '*mellitus*' meaning '*honeyed or sweet*' because in diabetes, excess sugar is found in blood and urine. In the 17th century it was known as the "pissing evil". The World Health Organization (2011) defines diabetes as a malfunction of the pancreas, where it does not produce enough insulin or the body has a problem in using insulin. Lack of insulin causes the blood glucose level to rise, with potential life-threatening results. There are two major types, namely types 1 and 2 diabetes. Up to 90% of those currently diagnosed have type 2 diabetes, with approximately 10% diagnosed with type 1 diabetes (Diabetes UK, 2004).

Type 1 diabetes: In type 1 diabetes, a person is completely dependent on insulin injections for survival because the pancreas produces very little or no insulin, which may lead to death. It is often genetically related and more common in children or young adults but can appear in adults as well (IDF, 2009). When the pancreas stops producing insulin, this causes excessive thirst, frequent urination, fatigue and acute illness that require immediate treatment and daily injections of insulin to sustain life.

Type 2 diabetes: Type 2 diabetes develops when the pancreas cannot produce enough insulin for the body's needs. The person is not dependent on insulin injections for survival, but they might be used (Vinicor and Bowman, 2004). Obesity, genetics, ageing and ethnicity are possible reasons for inadequate insulin levels, and treatment usually involves encouraging lifestyle, dietary changes and medication to either increase the secretion or promote the uptake of insulin, necessitating diabetes self-management. Therefore, as opposed to type 1, it is essentially preventable through lifestyle modification, that is, lifestyle choices largely play a part in causing this type of diabetes (Lindstrom *et al.*, 2006).

Another type of diabetes is **Gestational diabetes (GD)** which includes a spectrum of conditions with any degree of glucose intolerance with onset or first recognition during pregnancy (usually during the second or third trimester). In some women, GD develops because the body cannot produce enough insulin to meet the extra needs of pregnancy. In other women, it may occur during the first trimester of pregnancy. In these women, the condition most likely existed before the pregnancy (DUK, 2011). However, individuals with type 1 diabetes or type 2 diabetes detected for the first time during pregnancy are classified as having gestational diabetes.

Self-management is the person's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes as a result of living with a chronic condition (Mulcahy *et al.*, 2003)

Diabetes self-management education (DSME) is the on-going process of facilitating the knowledge, skill and ability for diabetes self-care. This involves the needs, goals and life

experiences of the person with diabetes and is guided by evidence-based standards. The overall objectives of DSME are to support informed decision-making, self-care behaviours, problem-solving and active collaboration with the healthcare team, as well as improve clinical outcomes, health status and quality of life. DSME is a critical element of care for all people with diabetes and is necessary to improve patient outcomes. The National Standards for DSME are designed to define quality diabetes self-management education and to assist diabetes educators in a variety of settings to provide evidence-based education (Funnel *et al.*, 2011).

Diversity refers to the quality of being different or varied or a point of difference, be it positive or negative difference. This concept incorporates acceptance and respect for one another by understanding that each individual is unique, and recognising each individual's differences such as ethnicity, race, gender, sexual orientation, socio-economic status, age, physical abilities, cultural beliefs, religious beliefs, political beliefs, or other ideologies (Dogra, 2010).

Ethnic Minority Group refers to a population group with an ethnic origin different from that of the majority population of the host country (Bulmer, 1996; Modood & Berthoud, 1997).

Culturally-competent diabetes care service refers to any diabetes care or health service that is tailored to the individual needs of EMGs by integrating the meaning of their culture into the intervention, whilst also taking into considerations their respective cultural and religious beliefs including their linguistic and literacy skills (Overland *et al.*, 1993; Resnicow *et al.*, 1999).

1.3. Diabetes health inequalities

Health inequality originates in the political, economic and social inequalities within a society and generally refers to the different health-related opportunities and resources available to individuals of a particular social class, gender, ethnic group or geographical area, with the result that the most disadvantaged groups suffer poorer health than the rest (Mackenbach & Bakker 2003; Marmot et al. 2008; Riccin-Cabello *et al.*, 2010). The significance of healthcare inequalities is predominantly seen in people with chronic or long-term illnesses, such as diabetes, because of their long-term relationship with the healthcare system (Wagner et al., 2001; Eakin et al. 2002; Riccin-Cabello *et al.*, 2010).

Diabetes is the fourth commonest cause of death globally. Its prevalence is rising at an alarming pace, affecting people of all ages especially EMGs, making it one of the most costly and challenging health problems in the 21st century (IDF, 2009; DUK, 2009; Masso Gonzalez *et al.*, 2009; WHO, 2011). The International Diabetes Federation (IDF, 2009) estimates that approximately 285 million (6.6%) adults worldwide, aged 20 to 79 years, have diabetes, of which around 70% live in low-and middle-income countries. Statistics from IDF Diabetes Atlas based on 170 data sources from 110 countries showed that 366 million people (8.3%) around the globe have diabetes (Shaw *et al.*, 2010; Whiting *et al.*, 2011). Although this demonstrates a good rate of diagnosis, it also highlights the challenges this may have to manage these increasing rates in any nation's healthcare system. If preventive measures are not taken, these numbers are expected to rise to 438 million (7.8%) of the adult population (IDF, 2009) and 552 million of the general population by 2030 (Whiting *et al.*, 2011). According to Whiting et al. (2011), the global total health expenditure on diabetes was at least USD 376 billion (12% of the world's total healthcare expenditure) in 2010 and is expected to reach USD 490 billion by 2030. However, this

expenditure varies by region, age group, ethnicity, gender, and country's income level, emphasising the health inequality in diabetes service provision globally.

There are considerable disparities between groups and regions because higher incidence, diabetes-related complications and higher mortality rates have been reported in EMGs and people with low socioeconomic levels (Brown *et al.*, 2004; Whiting *et al.*, 2011), perhaps due to the complex and specific cultural needs of the patients. The regions with the largest potential increases are those dominated by developing economies such as Asia and Africa, where diabetes rates are predicted to rise to two or three times more than countries with advanced economies and technologies (Oldroyd *et al.*, 2005). Countries with lower socioeconomic status and those belonging to EMGs receive poorer healthcare in the treatment of diabetes than the rest of patients in the world's most developed countries (Riccin-Cabello *et al.*, 2010) and experience worse diabetes control and higher rates of associated complications (Peek *et al.*, 2007). Furthermore, these groups have problems accessing effective diabetes care services to maintain a good quality of life, reduce complications and/or increase their survival chances when affected (Del Prato *et al.*, 2007). In developed countries like the USA and UK, the burden is also unevenly distributed across the population, with diabetes affecting racial and EMGs disproportionately. For instance, in the USA, the risk of being diagnosed with diabetes was 18% higher in Asians, 66% higher in Hispanics, and 77% higher in blacks than in whites (Centers for Disease Control and Prevention, 2011). Although EMGs with diabetes are generally less likely than the ethnic majority populations to receive appropriate care (Roberts, 2007; Del Prato *et al.*, 2007), results on ethnic differences in the quality of diabetes care and management in elderly adults are less clear. For example, some studies have found that ethnic minority elderly adults tend to have lower quality of care

and manage their diabetes less well than ethnic majority populations (Heisler *et al.*, 2007; Chou *et al.*, 2007; Richard *et al.*, 2012), whereas others demonstrated circumstances in which ethnic minority individuals reported higher quality of care and managed aspects of their diabetes better than ethnic majority populations (Richard *et al.*, 2012).

Similarly, in the UK, DUK (2006) examined the current link between diabetes and socioeconomic deprivation and found that the most affected communities were people from EMGs, people with severe mental illness with diabetes, prisoners with diabetes, homeless people with diabetes and refugees/asylum seekers, young people, the elderly and people in residential homes. These groups may find it difficult to reach mainstream channels, face inequalities in accessing care and their first language may not be English or they may have low literacy levels. Their cultures, religious beliefs and lifestyles (Patel *et al.*, 2001; Goenka *et al.*, 2007) may also affect diabetes healthcare delivery, leading to poorer diabetes self-management. Furthermore, the report demonstrated that people from deprived or ethnic minority communities were less likely to have their body mass index or smoking status recorded as well as records of their HbA1c, retinal screening, blood pressure, and neuropathy or flu vaccination. The least educated were more likely to have retinopathy, heart disease and poor diabetes control/higher HbA1c levels. The report recommended that the government and the NHS should adopt a long-term approach to diabetes, ensuring that interventions target diabetes in its early stages and address risk factors appropriately. Perhaps, one step towards reducing diabetes health inequality and improving health outcomes for EMGs is by improving accessibility and acceptability of these services. Research suggests that well designed health policies and interventions that successfully reduce inequalities in health outcomes are generally multi-faceted and holistic, and align with local priorities, ways of working and existing services (DUK, 2006).

However, the fact that many ethnic minority people with diabetes fall into the disadvantaged categories coupled with their complex and specialised needs would mean they are less likely to reverse the downward spiral, warranting further exploration of cultural barriers and potential solutions to improve access to healthcare and tackle health inequalities.

Although many official documents (NSF, 2001; ADA, 2001; DUK, 2006; IDF, 2009) encourage reducing inequalities in diabetes care provision in all populations, adequate systems and procedures are not often put in place to implement this. Consequently, EMGs are often considered vulnerable within their host country healthcare systems because their ability to master chronic diseases like diabetes can be hindered by barriers such as culture, linguistic differences, limited educational backgrounds, religious and health and illness beliefs. These groups do not always receive adequate diabetes care and services (Povlsen *et al.*, 2005a; Heisler *et al.*, 2007). With the increasing prevalence and disproportionate burden of diabetes globally, especially in EMGs, it has been noted that providing culturally-appropriate interventions by culturally-and linguistically-competent healthcare professionals (HCPs) can confer important benefits to the person with diabetes and their families and also reduce costs in every nation's healthcare system (Wolf *et al.*, 2007). Improved responsiveness to the health beliefs, practices and cultural needs of diabetes patients is needed for them to have equitable access to diabetes care services, tailored to their individual needs, with such provision recognising that both the service provider and the ethnic minority patient often bring their respective learned patterns of language and culture to the healthcare experience (Szczepura, 2005).

1.4. Background to the clinical/scientific problem and justification for the research

1.4.1. The UK national picture, impact and diabetes prevalence

Diabetes is a chronic metabolic condition requiring a life-long learning process for patients and healthcare professionals, making it a major health issue. It has major social-economic implications for the NHS (Cradock, 1999; DH, 2003; Christopher and Kendrick, 2004; Roberts, 2007) because of the considerable costs associated with the management of its resulting complications. Effective diabetes management has been shown to reduce the risk of complications (Stratton *et al.*, 2000). However, when diabetes is not well managed, it is associated with serious complications including heart disease, stroke, blindness, kidney disease and amputations leading to disability and premature mortality. By the time they are diagnosed, half of the people with Type 2 diabetes show signs of complications (UKPDS, 1991, Roberts, 2007). Complications may begin five to six years before diagnosis and the actual onset of diabetes may be ten or more years before clinical diagnosis (Harris *et al.*, 1992). The national financial cost of managing diabetes and associated complications to the NHS is substantial, likewise costs to the lives of people with diabetes and their families, nearly £10 billion per year, that is, 10% of the total NHS budget (DUK, 2009; Khunti *et al.*, 2009; DUK, 2010a) and, as such, has been recognised as an essential health priority (Roberts, 2007; DUK, 2010a). There is evidence to suggest differences in access to healthcare in general and diabetes care services in particular in the UK for different ethnic groups, but little research examining the differences and reasons for the health inequalities and the cultural factors responsible for poor adherence to professional advice in care management as well as service uptake in EMGs with this disease (DUK, 2006; Khunti *et al.*, 2009).

DUK (2010) estimates that more than 2.8 million people in the UK are diagnosed with diabetes, with approximately 400 new diagnoses daily. It is projected that this number will reach 4 million by 2025 if preventive measures are not taken. Staggering figures from epidemiological data between 1997 and 2003 have shown type 2 diabetes increasing at a faster rate in the UK (74%) compared to the USA (41%) (Masso Gonzalez et al., 2009). In the UK, the number of EMGs with diabetes is higher, compared with the British Caucasians. A UK study reported diabetes prevalence rates of 11% to 20% in South Asians and 15% in African-Caribbeans as compared to 1% to 5% in white Caucasians (Baradaran & Knill-Jones, 2004). People of South Asian origin living in the UK are up to six times more likely than white Europeans to develop diabetes and are also affected by diabetes at a younger age (DH, 2006). Diabetes develops 5 to 10 years earlier in these populations compared with white Caucasians and is often associated with established complications, such as cardiovascular diseases, at diagnosis, leading to premature and high mortality (Mather *et al.*, 1998; Khunti *et al.*, 2009; Gholapa *et al.*, 2010). Besides environmental and lifestyle changes, the higher prevalence of type 2 diabetes in EMGs, particularly the South Asian population, is partly attributed to a stronger genetic predisposition and insulin resistance (Mohan, 2004; Barroso, 2005; DUK, 2011).

Unlike type 1 diabetes, which is mostly genetically related, type 2 diabetes usually develops in white people over the age of 40, though in South Asian people, who are at greater risk, it often appears from the age of 25. It is also progressively becoming more common in children, adolescents and young people of all ethnicities and in some cases, it has been found to have developed in children as young as seven (DUK, 2011). Being overweight or obese (body mass index of 30 or greater) increases the risk of developing type 2 diabetes. In particular, adipose tissues or fat around the abdomen puts the

individual at increased risk as it releases chemicals that can upset the body's metabolic and cardiovascular systems, thereby increasing the risk of developing various conditions, including heart disease, stroke and some types of cancer (DUK, 2011). In this type of diabetes, DUK (2011) recommends the maintenance of a healthy weight through a healthy lifestyle including balanced diet and regular exercises as ways of preventing and managing diabetes. However, differences in lifestyle habits of EMGs, especially South Asians and white Europeans are well known (Hanif and Karamat, 2009). *Do EMGs understand the implications of having diabetes and the importance of healthy lifestyle?*

The UK evidence shows that most EMGs live in socially deprived areas and have lower literacy levels and language barriers, which may impede access to diabetes care (Bellary & Barnett, 2007). The evidence further reveals the inadequate quality of healthcare for EMGs, primarily because of a strong cultural element associated with the provision of healthcare and some NHS staff may lack sufficient cultural competences (Hawthorne et al. 1993; Narayan *et al.*, 1997; Cone *et al.*, 2003; Brown *et al.*, 2006; Zeh, 2010). In addition, one systematic review reported difficulties in accessing and using health services by some British South Asians (Hawthorne, 1994), who described instances of racial discrimination in provisions of care services (Hanif and Karamat, 2009). All these factors result in poor disease management, low adherence to treatment, poor outpatient / education attendance, poor glucose control and low compliance with medication (Johnson *et al.*, 2000; Oldroyd *et al.*, 2005). National evidence also shows that 50% of people with diabetes have one or more of the associated diabetes complications on diagnosis, which could have been prevented with early diagnosis and good glycaemic control (DUK, 2006; Roberts, 2007).

1.4.2. The choice of Coventry for the study

The city of Coventry (12th largest city in the UK) was chosen as it represents a typical UK city with relative affluence alongside pockets of severe deprivation coupled with health inequalities. Most EMGs (around 1 in 10 people of African-Caribbean (AC) and South Asia (SA) origins) live in socially deprived areas with high illiteracy levels and language barriers. According to the 2011 census, approximately 14% of the Coventry population are people from AC and SA origins. Approximately 1.2% of the residents are Chinese while 0.6% are Arabs. Residents from African origins have seen the highest increase from 0.6% in the 2001 census to 4% in the 2011 census. The number of residents from Eastern Europe, though unknown, is believed to be fast rising. The Public Health Annual Report (2010) counted 66 general practices in Coventry, with a number of single-handed (run by lone) Asian General Practitioners (GPs), providing healthcare to the over 360,000 registered people. Over 35% of all residents fall into the most deprived 20% nationally. In Foleshill (the centre of the Asian community), 100% of people fall into this category. Diabetes prevalence varied by practice from 1.42% to 7.64% in 2009/2010. The standardised admission rates for chronic conditions usually managed by primary care are high compared to rates for the West Midlands and England.

The 2006 diabetes prevalence in Coventry was approximately 3.5% (n=12,000) with proportionally higher rates in EMGs (Barker, 2006). Quality Outcome Framework (QOF) (2011) data put the figures at 16,000 out of the 361,850 residents (4.4%) registered with a GP in Coventry. However, the Yorkshire & Humber Public Health Observatory (YHPHO) on the PBS Diabetes Prevalence Model estimates the prevalence to be 5.7% (19,000 individuals). Although the number of people with diabetes from EMGs is unknown, the

prevalence including undiagnosed diabetes is higher. In Coventry, people of AC and SA origins are up to three times and six times respectively more likely to develop type 2 diabetes than the majority white British (Barker, 2006; Grainger, 2010).

In Coventry, ethnicity and associated lack of awareness are assumed to be factors that favour high level of undetected diabetes. Rising levels of obesity and a relatively young population point towards diabetes becoming even more widespread over time in Coventry (with approximately 23% of the population being clinically obese). If effective preventive measures are not taken, PBS predicts that the number will continue to rise dramatically.

In the late 1980s, Coventry healthcare services were not always patient-centred as they were lacking in culturally-appropriate and linguistic provision (Goodwin *et al.*, 1987). This appears to be continuing almost three decades later, warranting this research in Coventry to investigate these factors and suggest recommendations to reduce health inequalities and the economic burden of diabetes and its associated complications to the NHS. To mitigate this, the Coventry Public Health Annual Report (2010) recommends a service model that describes the competencies and skill levels by practices to ensure effective utilisation of diabetes services but falls short of recommending or adopting a model that allows for the needs of different ethnic minority populations to be addressed locally.

Therefore, by using Coventry as a representative case study of UK cities, this study will attempt to investigate cultural barriers and identify solutions, which could be implemented to address the cultural diversity of the local population and be transferable to similar national and international geographical and demographic settings and other healthcare contexts.

1.5. Diabetes self-management support in ethnic minority groups

Self-management support (SMS) will be referring to the process of making and refining multi-level changes in the community and healthcare systems or interventions to facilitate patient self-care. It is increasingly becoming important in providing on-going support to sustain self-management achievements made by patients as a result of education (Funnell *et al.*, 2007). Incorporating SMS into education programme structure may sustain important benefits of healthcare interventions (Mulcahy *et al.*, 2003). Traditionally, glycaemic control was achieved by pharmacological interventions (Norris *et al.*, 2002). The UKPDS study highlighted the need for alternative approaches to achieving long-term glycaemic control over a decade ago, which demonstrated worsening metabolic control over time (Turner *et al.*, 1998). This ushered in many new ways of dealing with the problem, including diabetes educational support. Because of the causal link between diabetes, especially type 2 diabetes and lifestyle factors, global clinical guidelines have emphasised the importance of prevention, including structured and continuous appropriate education and self-management support (SMS) from the point of diagnosis (DH, 2001; NICE, 2003; National Collaborating Centre for Chronic Conditions (NCCC), 2008; IDF, 2009). Studies have demonstrated the importance of structured diabetes education in the promotion of health practices that could prevent or delay potential diabetes complications (Strine *et al.*, 2005; Singh *et al.*, 2005, Davies *et al.*, 2008; Sturt *et al.*, 2008) and improve biomedical and overall psychosocial outcomes in patients with type 2 diabetes (Brown, 1999; Steed *et al.*, 2003; Davies *et al.*, 2008). These authors also reported that people who received diabetes self-management education (DSME) compared with usual care were significantly more likely than those who did not, to have the following: had a flu vaccine, checked their blood sugar daily, had their feet and HbA1c level checked in the

previous year as well as being physically active. However, most of these studies were conducted in the majority ethnic populations and used English as means of communication and, despite the high prevalence of diabetes in EMGs, EMGs appear to be under-represented in such research. It is important to note that two systematic reviews involving EMGs with diabetes (Khunti *et al.*, 2008; Hawthorne *et al.*, 2010) identified a diverse useful range of interventions: tailored clinic appointments, multilingual link workers, culturally-adapted education, use of non-written materials (such as flashcards), medication reviews with bilingual workers, self-help groups, specialist professionals (such as dieticians, diabetes nurses, podiatrists and psychologists) providing tailored care and tailored lifestyle interventions. The meta-analysis undertaken in the review by Hawthorne *et al.* (2010) found benefits of these interventions diminishing over time. High levels of heterogeneity in the interventions and study designs were reported by the Khunti *et al.* (2008) review.

As diabetes is a challenging lifelong condition to the sufferer and all stakeholders, one way of alleviating this burden is for healthcare professionals to provide adequate SMS, and to ultimately promote self-management (Wagner *et al.*, 2001). People with diabetes need the knowledge, skills and confidence to manage their own health to the degree they feel comfortable with. This needs a culture change for both the people with diabetes and healthcare professionals to learn new ways of working together so as to prevent and/or minimise the complications of heart disease, kidney disease, amputations and blindness (Young and Roberts, 2011). To promote effective management and minimise these diabetes-related complications, the sufferer has to adopt and sustain lifestyle changes, modify behaviours and adhere to sometimes, continuous intensive treatment regimens, such as insulin therapy for life (Mulcahy *et al.*, 2003). Evidence shows that all these

modified life circumstances occur away from the supportive clinical settings but in the individual's own personal environment, be it at home, workplace or school, where the daily challenges of everyday life can take precedence over diabetes management (Penckofer *et al.*, 2007). Personal responsibility and lifelong commitment to self-management are therefore crucial, which can only be ensured through effective knowledge of the condition and skills acquired from trained healthcare professionals/educators proficient in diabetes education (Norris *et al.*, 2001). The NSF for Diabetes (DH, 2001) recognised this knowledge gap and the importance to support people to look after themselves as caring for yourself, or 'self-care', is fundamental to daily living. For people with diabetes, it is about dealing with the impact of this disease on a daily basis. There is increasing evidence that supporting people with long term conditions, such as diabetes, to care for themselves leads to improvements in clinical outcomes and in their quality of life (Wagner, 2001; DUK, 2006; Joshi *et al.*, 2010). Can the implementation of SMS improve diabetes self-management in EMGS?

The goal of SMS is to optimise metabolic control, prevent acute and chronic complications and enhance quality of life (Norris *et al.*, 2002; Anderson and Christison-Lagay, 2008) by helping patients acquire the knowledge, information, self-care practices, coping skills and attitudes required for effective self-management of their diabetes (Tang *et al.*, 2006). A meta-analysis review of diabetes self-management interventions found benefits of using SMS and concluded that although education alone does not lead to improved outcomes, self-management interventions can improve glycaemic control (Norris *et al.*, 2002). However, in practice, it is often not possible to replicate clinical trials' findings due to many challenges, including the fact that the interventions are not well resourced and not generally designed to meet the needs of EMGs or the underserved populations due to

their cultural and linguistic barriers (Anderson and Christison-Lagay, 2008). It is therefore crucial to understand these barriers in order to promote diabetes self-management in ethnic minority populations. The American Diabetes Association recommends assessment of self-management skills and knowledge of diabetes at least yearly, and the provision or encouragement of continuing diabetes education (ADA, 2001). The diabetes standards enforcing the quality of care stipulate that the standards should be periodically reviewed and revised by diabetes experts to reflect current scientific knowledge and healthcare needs (Mensing *et al.*, 2000).

In line with international guidelines, the UK diabetes health policy (DH, 2001; NICE, 2003) since late 1990s has concentrated on encouraging people to become more knowledgeable about their condition and treatment regimen and improving the self-management abilities of people with diabetes (Sturt *et al.* 2005). However, the impact remains low, especially for EMGs with diabetes, due to limited structured culturally-competent diabetes education programmes, [such as Diabetes Education and Self-Management for Ongoing and Newly Diagnosed [DESMOND] (Skinner *et al.*, 2006; Davies *et al.*, 2008), Dose Adjustment For Normal Eating [DAFNE] (Heller *et al.*, 2002; Rogers *et al.*, 2009), Diabetes Manual (Sturt *et al.*, 2008), and others], around the country and in Coventry, in particular, which is the primary research site. These models usually incorporate self-efficacy and empowerment strategies, based on social learning theory, with an emphasis on patient involvement within the structured programme (Forbes *et al.*, 2010).

In the UK, a number of structured education programmes, such as DESMOND, X-PERT and DAFNE, meeting the NICE 2003 quality criteria are being delivered in the mainstream

healthcare settings, predominantly in English, which is often seen as one of the cultural barriers to engage EMGs in service uptake. Whilst it is recognised that these traditional educational programmes may not work for most ethnic minority populations due to a number of cultural and linguistic barriers, there are few examples of successful structured education approaches to engage these populations and improve their diabetes-related outcomes. The best known areas/teams that have tested structured culturally sensitive education programmes with ethnic minority populations, known to this author include: the Leicester diabetes team led by Professors Melanie Davies and Kamesh Khunti of Leicester University has been delivering DESMOND - Black and Minority Ethnic (BME) [an education course available in English as well as in Gujarati, Punjabi, Urdu and Bengali] in Leicester City since April 2009 (Mistry, 2010). This Leicester team and their partners have been working on '*DESMOND Foundation Study - A randomised controlled trial of the DESMOND Foundation Programme for people with established type 2 diabetes in a multi-ethnic population in Leicester and South Birmingham.*' This RCT (July 2010 – June 2012), which aimed to recruit 640 participants (320/320 in each arm of intervention and usual care), is testing the effectiveness of the DESMOND Foundation programme in a multi-ethnic population with established type 2 diabetes with 'changes in HbA1C' as the primary outcome. Participants in the intervention arm will attend a DESMOND Foundation Programme delivered in either English or with facilitation in a South Asian language (Gujarati, Urdu or Punjabi) with follow-up at six and 12 months (Davies *et al.*, 2011).

Similarly, structured education using multilingual link workers had been successful (Hawthorne and Tomlinson, 1997; Moss *et al.*, 2008). The Birmingham Community Healthcare is tailoring DESMOND diabetes education programme to people of South Asian origins with limited English-speaking skills by translating key instructions into Urdu,

Bengali, Gujarati and Punjabi (<http://www.bhamcommunity.nhs.uk/news-archive/diabetes-bme-desmond/>). Another structured culturally specific self-management education programme for EMGs is the X-PERT Tower Hamlets programme, developed to specifically target local Muslims in providing diabetes information using DVD and website both at home and healthcare settings in appropriate languages. Apart from the X-PERT programme, whose resources have been piloted and found to be extremely effective at providing advice and raising awareness of diabetes in the Muslim community (Diabetes Update, 2010), it is not clear if the impact of the other education programmes involving EMGs have been evaluated in order to be transferable to similar communities nationally. Nonetheless, it could be argued that structured culturally sensitive diabetes education programme delivered in appropriate language would be beneficial to these people, as it can allow them to fully engage with their providers as they would ensure language and cultural concordance. Whilst the DESMOND-BME targets only South Asian people with type 2 diabetes, X-PERT provides structured education to people with both type 1 and type 2 diabetes. *If there is lack of culturally-competent HCPs/diabetes educators to ease the cultural barriers experienced by EMGs, could lay ethnic minority people with specific ethnic language competencies be trained to deliver this prescriptive education programme to patients with diabetes from the same ethnic backgrounds?* Studies have acknowledged the inclusion of cultural sensitivity in education interventions aimed at EMGs to be more meaningful (Stone *et al.*, 2005; Stone *et al.*, 2006; Hawthorne *et al.*, 2008; Khunti *et al.*, 2008).

1.6. The researcher and motivation for the research topic

The researcher is a senior Registered General Nurse with over fifteen years healthcare experience in both primary and secondary care in the NHS, coupled with clinical

governance, clinical risk management, mentorship, teaching and project management experience. Prior to registering for this PhD fellowship with Warwick Medical School (WMS), the researcher was a Clinical Research Facilitator with the Warwickshire Institute for Diabetes, Endocrinology and Metabolism (WISDEM), with primary responsibilities for conducting and coordinating clinical research in accordance with GCP as well as writing up research grants applications.

Being from an ethnic minority group himself, his passion in undertaking this research is personal, professional as well as academic. In his quest to understand this area, a pilot general practice survey (Zeh, 2010) was conducted in 2009 to identify how local practices in Coventry deliver diabetes services to EMGs (see publication, Appendix 1 for details). This survey of four practices reported cultural barriers to diabetes service uptake and found no form of structured education programme specifically for EMGs with diabetes. The way forward to mitigate these issues was limited and the survey recommended further exploration and the need to extend the survey to all the 66 general practices in Coventry in order to have a clearer picture of the situation. The findings from this survey were widely disseminated locally and nationally and published in the Diabetes and Primary Care Journal in October 2010. This work, in addition to the researcher's special interest in diabetes and ethnicity, became a motivating factor for him to apply for a Clinical Doctoral Research fellowship titled '*The Coventry Delivering Diabetes Care (DDC) Project: Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups*' with the National Institute for Health Research (NIHR) in April 2009, which was unsuccessful. This application was revised based on NIHR feedback and submitted for the NHS West Midlands Nurses, Midwives and Allied Health Professionals

(WMNMAHP) Research Training Fellowship in June 2009, which was awarded. The fellowship training commenced with WMS in January 2010.

Therefore, further exploration of this area of research has the potential of bridging the gaps in accessing healthcare services between this group of people and the majority white population and empowers them to become more proactive in taking part in clinical trials, where EMGs are significantly under-represented. As this group of patients becomes better informed, it may lead to a reduction in NHS healthcare spending, as well as improved patient and staff satisfaction. The researcher's overall vision is that the research findings, if warranted, should be applied in clinical practice to ultimately improve the lives of patients with diabetes. This vision, coupled with a strong belief in evidence-based practice, arose from working with NHS staff and caring for patients with diabetes in the NHS, and understanding the problems they encounter in diabetes management in EMGs, especially empowering them to develop self-efficacy, (individuals' belief in their own ability to complete specific tasks, deal with certain situations and achieve goals), to promote self-management. The researcher's work experience in the proposed research area, together with personal attributes and collaborators, are further motivations. The positive partnership and collaboration between WMS and UHCW NHS Trust were additional motivating factors in the topic selection as 'diabetes' is included in their research strategy.

1.7. Naming and launching of the project

This section describes the process of adopting the project name, including the stakeholder event used to present the findings from the pilot General Practice survey and to discuss the next steps appropriate for the locality.

In one of the Warwick Medical School Master's degree modules (Patient and Public Involvement) in February 2010, in which the researcher participated, the aims of this research were explained to the group members (who were mostly healthcare professionals), with the intention of choosing a new name for the project to replace DDC (Delivering Diabetes Care), which was originally used to apply for the research fellowship. Group members proposed four acronyms: CODDCEMG (Coventry Delivering Diabetes Care to Ethnic Minority Groups), CODE (Coventry Delivering Diabetes Care to Ethnic-minority-groups), CODDCEM (Coventry Delivering Diabetes Care to Ethnic Minorities), DEDICATED (Delivering Diabetes Care To Ethnic Diversity). DEDICATED was preferred by most participants as well as the entire research team and therefore adopted for the study.

The DEDICATED project was officially launched at Allesley Hotel, Coventry, in March 2010 before 50 stakeholders/delegates including GPs, nurses, practice managers, healthcare commissioners, allied healthcare professionals, patient representatives and academic staff from the NHS, academic institutions and the Coventry community. This half day educational event was interactive and aimed to share the findings from the pilot survey (Zeh, 2010) and to seek the views of the stakeholders on how best the project could work for the locality to benefit patients as well as improve diabetes care in primary care. The meeting, supported by an educational grant from TAKEDA Pharmaceutical, included prominent speakers from DEDICATED, Warwick Medical School, Apnee Sehat CIC and Coventry community on various aspects of diabetes management in EMGs (see photo of speakers and sponsors in Figure 1 and meeting programme in Appendix 2).

The pilot study findings were presented by this researcher. To engage stakeholders in the discussion, the researcher and one of his supervisors gave brief presentations on various parts of the project. This was followed by two ethnic minority patient representatives (a female and a male), who were involved in the designing of the general practice survey and shared their views on the project and their experience of living with diabetes. The stakeholders suggested ideas which were collected in a flip chart paper and analysed by this researcher, and this enhanced the development of the PhD research questions. The project was generally perceived by stakeholders as useful but they (especially GPs) felt that time constraints do not always permit primary care staff to fully support research initiatives. However, they promised to help the project achieve its objectives as it could potentially benefit the local community, especially EMGs with diabetes.

The central themes that emerged were: most ethnic minorities in Coventry live in socially deprived areas and have specialised diabetes care needs due to language and cultural barriers; diabetes services should be tailored to the individual needs as 'one size does not fit all'; we have medications which are not suitable for all patients and healthcare professionals need to be careful when prescribing; lifestyle changes are paramount to ensure effective glycaemic control; individual patients empowered by healthcare professionals in a culturally sensitive manner can take personal responsibility for their diabetes; health promotion is key as prevention is better than cure.

Figure 1.1: Photo of speakers and sponsors at the launch event.



1.8. Previous literature and systematic reviews

Limited research studies have explored the impact of cultural barriers in accessing effective diabetes care and services and/or the implementation of culturally-competent healthcare service interventions on improving diabetes health related outcomes in EMGs. Very little is known about how these barriers may operate in particular societies; some service providers do not appear to appreciate the nature of these barriers or how they may prevent members of EMGs from receiving patient-centred diabetes care (DH, 2001; Roberts, 2007). Perhaps the best known reviews/systematic reviews in diabetes and EMGs have been carried out by Hawthorne et al. (1993), Oldroyd et al. (2005), Davies (2006), Hill (2006), Saxena et al. (2007), Whittemore (2007), Khunti et al. (2008), Alam et al. (2008), and Hawthorne et al. (2010). These reviews investigated the impact of cultural/linguistic barriers in accessing effective diabetes care services and/or the effectiveness of diabetes related interventions with regard to culturally-appropriate competencies, and reported varied effects in health-related outcomes. Their findings are inconsistent due to the types of studies included and the heterogeneity of the ethnic

minority populations investigated. Furthermore, the reviews varied in methodological quality, such as search strategies, with some methodological flaws, for example, no inclusion criteria (Hawthorne *et al.*, 1993; Davies, 2006; Hill, 2006; Oldroyd *et al.*, 2005) and single authored (Davies, 2006; Hill, 2006; Whitemore, 2007). Each of the reviews answered different questions.

To illustrate, Hawthorne *et al.* (1993) focusing on '*cultural and religious influences in diabetes care in Great Britain*' examined some of the dietary customs that can affect glucose control, problems with communication and diabetes education, and a brief description of health beliefs commonly held by Asian patients that can help physicians to understand some of the reasons for poor compliance with accepted western medicine. The review demonstrated that type 2 diabetes was four times more common in the South Asian population than in the white English Caucasians and that British Asians with diabetes have poorer blood glucose control, awareness of diabetes management, and knowledge of complications. They attributed these to their cultural and religious backgrounds, and communication problems. The review recommended further studies involving South Asians and African-Caribbean communities whose health beliefs and health needs were less understood by healthcare professionals and the majority White population. Another systematic review by Oldroyd *et al.* (2005) found that GP consultations were higher in South Asian and African-Caribbean adults compared with the general population, although no account was taken of differences in morbidity. Barriers to care included poor understanding of the severity of symptoms, poor communication, knowledge of the value of preventative care, knowledge about the availability of services. South Asians were found to be less likely to be given follow-up GP appointments, to be

offered district nurse services, and have had previous cardiological consultation. The authors recommended an urgent need for studies using culturally specific interventions.

Other reviews focused on reviewing culturally-competent education interventions in EMGs with diabetes and reported varied effects in health-related outcomes (Saxena *et al.*, 2007; Khunti *et al.* 2008; Alam *et al.*, 2008; Hawthorne *et al.*, 2010). Two of these reviews found that structured diabetes education programmes are central to effective diabetes self-management (Alam *et al.*, 2008; Khunti *et al.* 2008). Another review suggested that diabetes self-management interventions effective in the general population, when modified to be culturally-competent, can improve health-related outcomes in EMGs (Whittemore, 2007).

Although these reviews provided some insight into cultural barriers and the impact of culturally-competent healthcare interventions, two major questions seemed to have received less attention;

- (a) What are the cultural barriers of and how do they impede members of EMGs from receiving effective diabetes care services?
- (b) How could health care professionals or health workers in general work with EMGs to provide effective culturally-competent care and services tailored to the needs of EMGs with diabetes?

Therefore, this PhD thesis will build upon the proposed research design and methodological approaches below.

1.9. Proposed research design and methodological approaches

1.9.1. Proposed research questions/aims/objectives

The primary research question is: How could healthcare professionals or health workers in general work with EMGs to provide effective culturally-competent care and services tailored to the needs of EMGs with diabetes?

This question led to the following aims/objectives:

- 1) Identify cultural barriers to, and opportunities for, providing access to effective diabetes care to EMGs;
- 2) Examine the impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in EMGs;
- 3) Investigate diabetes primary care service provision to EMGs and their commissioning in a typical ethnically mixed medium-sized UK city from the perspective of service providers;
- 4) Develop and implement a culturally-competent service tailored to the individual needs of EMGs with diabetes within case study practices;
- 5) Provide recommendations on delivery and commissioning of diabetes care services to meet the needs of EMGs locally and nationally.

1.9.2. Study design / investigation plan

A combination of methods using systematic reviews, quantitative and qualitative techniques and consisting of the following methods:

- a) Systematic reviews (Chapters Two and Three),
- b) Cross-sectional (General Practice) survey (Chapter Five),
- c) Participatory research within case study general practices (Chapter Six),

- d) Qualitative interviews with patients and healthcare professionals (Chapter Six).

1.10. Importance of answering the proposed research questions to the NHS

This study is important and relevant to the NHS and social services for the following reasons:

- i. Diabetes (more susceptible in EMGs) is a chronic condition with wide social and economic implications for the NHS,
- ii. Coventry is typical of a large developed world city with deprivation, ethnic minority populations and pressure on healthcare services.
- iii. Ethnic minority patients have poorer disease management and poorer health-related outcomes,
- iv. Providing high quality and equitable patient-focused care and services which reflects the UK cultural diversity continues to be a major challenge to the NHS,
- v. There is a strong cultural element associated with the provision of care to the entire city of Coventry, which impedes access to healthcare and further gives rise to differences in health experience.

Therefore, exploring these research questions will make it possible to (a) highlight existing barriers that compromise the care of ethnic minority people with diabetes, (b) provide direction to exploring solutions that ultimately lead to the implementation of better diabetes care services to improve the health of ethnic minority people with diabetes and reduce their chances of developing diabetes complications and (c) ensure that findings will be applicable and transferable to other NHS settings. Should cultural barriers be better understood and the impact of culturally-competent diabetes interventions explored, they may improve the planning and commissioning of culturally appropriate diabetes care

services tailored to the needs of EMGs.

1.11. Chronology of the research / Outline of chapters

This PhD thesis describes a forty-two month funded fellowship by NHS West Midlands that builds on an earlier pilot study supported by TAKEDA Pharmaceutical Limited, completed and accepted for publication prior to the commencement of the PhD, but which informed the designing of this research (Appendix 1). The thesis is set out as four linked but independent research studies. The detailed research methods for answering each of the above questions (1-4) and settings are described within each chapter. One overarching methodology chapter provides the framework for the approaches to the research design of the individual studies and the overall research thesis. References are given at the end of the thesis using the Harvard (WMS) referencing style in alphabetical order of first author.

Chapter One is the introduction to the research (background, aims, and the areas examined in order to address the research questions). Furthermore, the chapter presents the big picture of health inequalities in diabetes service provision by examining the clinical problem, the size, SMS and impact of diabetes in ethnic minority populations in the UK and the choice of Coventry as the main investigation site, including the researcher's motivation to the topic as well as the importance of the research to the NHS.

Chapter Two presents a systematic literature review entitled 'cultural barriers impeding EMGs from accessing effective diabetes care services.' The chapter addresses research question/aim 1 above. This review has been accepted for publication by Diversity and Equality in Health and Care journal and the publication is planned for March 2014.

Chapter Three presents a published international multi-ethnic minority-based systematic review entitled 'The impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in EMGs' as a means to overcome the cultural barriers reported in Chapter Two. It presents a Culturally-Competent Assessment Tool (CCAT) developed by the researcher to systematically assess the cultural competency of each intervention. The paper comprising this chapter was published in Diabetic Medicine journal in October 2012 and is attached as appendix 3 (Zeh *et al.*, 2012), and addresses research question/aim 2.

Chapter Four presents the methodological approach taken to conduct this research. It details the research designs pertaining to the systematic reviews, cross-sectional survey, and participatory research.

Chapter Five builds on evidence from the two systematic reviews and the earlier pilot general practice study to develop and execute a general practice survey across a single case multicultural UK city (Coventry) with high diabetes health needs. The survey, which mainly addresses research question/aim 3, aims to understand/explore/determine diabetes primary care service provision to EMGs and their commissioning from the perspective of service providers across the whole city of Coventry.

Chapter Six presents the Participatory Research (PR), which took place in a single case study Coventry General Practice site with high EMGs registered patients and low current levels of self-assessed culturally competent care provision as assessed on the survey presented in Chapter Five. The PR primarily focuses on research question 4, which aims

to design an effective culturally-competent diabetes care service framework for this general practice.

Chapter Seven presents the discussion of the research findings from each study and the overall thesis. The strengths and limitations of the study are considered, as well as the relationship of the findings to wider empirical and policy research.

Chapter Eight (summary of the research findings) reports the conclusions and recommendations for research, policy and practice. This chapter predominantly addresses research question/aim 5.

CHAPTER TWO

CULTURAL BARRIERS IMPEDING ETHNIC MINORITY GROUPS FROM ACCESSING EFFECTIVE DIABETES CARE SERVICES: A SYSTEMATIC REVIEW OF OBSERVATIONAL STUDIES

Zeh, P., Sandhu, H. K., Cannaby, A. M. and Sturt, J. A. Diversity and Equality in Health and Care Journal (In press).

2.0. Abstract

Background/aim: Cultural barriers have been found to prevent members of EMGs from accessing diabetes services but little is known about the specific nature of these barriers. This systematic review of observational studies aimed to identify and explore cultural barriers as a basis for improvements in care.

Methods: Articles from 4 databases (Medline, CINAHL, Cochrane, DARE) from inception to September 2011, two National Health Service specialist libraries (diabetes, ethnicity and health), and Warwick Medical School publications were retrieved, together with reference lists for these papers. Inclusion criteria were qualitative or quantitative studies, excluding randomised controlled trials, involving EMGs with diabetes within a global majority population. Two reviewers independently conducted paper selection and appraisal.

Results: 316 studies were retrieved and 22 included in the review. Due to the heterogeneity of the studies, a narrative analysis was undertaken. Eight key cultural issues emerged for effective diabetes care and management to EMGs:

- Cultural adherence to diet, exercise, and social interactions
- Commitment to religious beliefs
- Linguistic differences between patients and health workers
- Low health literacy levels
- Different beliefs about health and illness
- Belief in expert and professional support
- Low accessibility of culturally appropriate services/information
- Low concordance with Western professional advice

Conclusion: Cultural issues were identified to compromise the level of diabetes care services received by EMGs. It is recommended that further attention be given to the development of culturally-competent interventions for improving access to health care and diabetes outcomes for members of specific EMGs.

2.1. Introduction

Diabetes is a long term, serious and challenging metabolic condition and a major health issue worldwide. Whilst diabetes affects every society, some populations are particularly susceptible but also lack understanding of the condition (Baradaran & Knill Jones, 2004; IDF, 2009; Alam *et al.*, 2012). Evidence suggests that, where members of susceptible populations are in the minority, they may not receive equitable diabetes care; this is attributed to a mixture of cultural factors and some service providers' lack of cultural competence (Hawthorne *et al.*, 1993; Narayan & Rea, 1997; Cone *et al.*, 2003; Brown *et al.*, 2002; Zeh, 2010; Mainous *et al.*, 2007). The National Service Framework for Diabetes stipulates the minimum standards of diabetes care to be offered to all patients, irrespective of ethnicity, language, culture, religion, gender, disability, age and location [Department of Health (DH, 2001)]. Health care practices should be designed to ensure that health workers take into account the individual patient's background and deliver tailored services (Cone *et al.*, 2003; NHS-Health-Scotland, 2004). However, few studies have explored the impact or effects of cultural and linguistic barriers that may compromise the quality of care delivered to members of EMGs with diabetes (Davies, 2006; Hill, 2006; Fleming & Gillibrand, 2009). Little is known about how these barriers may operate in particular societies; some service providers do not understand the nature of these barriers or how they may prevent EMGs from receiving patient-centred diabetes care fundamental to diabetes care (DH, 2001; Roberts, 2007; Wilson *et al.*, 2012). A better understanding of these cultural issues may guide healthcare commissioners and clinical commissioning groups (CCGs) to effectively reconfigure diabetes services in primary care, which may improve both care service engagement and outcomes in minority populations (NHS-Health-Scotland, 2004).

In this review, culture is defined as a shared system of values, beliefs, identities, traditions, behaviours, verbal and nonverbal patterns of communications that bind a group of people together and differentiate them from other groups (Salimbene, 1999). It encompasses beliefs, language, social norms and values including practices which can create a sense of social support and belonging for individuals sharing the same core beliefs. These can both facilitate and impede health coping styles, access to and utilisation of healthcare services and implementation of professional advice. This study focused on the cultural barriers in accessing and use of diabetes services. Also in this review, EMGs refer to a population group with an ethnic origin different from that of the majority population of the host country (Bulmer, 1996; Modood & Berthoud, 1997).

Scoping searches identified ten reviews reporting cultural barriers among members of EMGs with diabetes. Two were systematically conducted reviews (Brown *et al.*, 2002; Fleming & Gillibrand, 2009) and eight were literature reviews with some methodological flaws, for example, no inclusion criteria (Hawthorne *et al.*, 1993; Davies, 2006; Hill, 2006; Gohdes, 1988; Brown, 1997; Oldroyd *et al.*, 2005; Greenhalgh, 2008; Greenhalgh, 1997) and single authored (Davies, 2006; Gohdes, 1988; Brown, 1997; Greenhalgh, 2008; Greenhalgh, 1997; Hill, 2006). Although these reviews provide some insight into cultural barriers, two important questions seem to have received less attention, which the current review aims to address:

- a) What and how do specific cultural barriers impede members of EMGs from receiving effective diabetes care services?
- b) What can be done to minimise these cultural barriers?

2.2. Methods

2.2.1. Data sources, search strategy and eligibility

CINAHL and MEDLINE (NHS Evidence) databases were searched from inception to September 2011, using the search terms in Table 2.1. In addition, searches were conducted using Cochrane and DARE databases, two NHS specialist libraries based at Warwick University for diabetes (www.library.nhs.uk/diabetes), and ethnicity and health (www.library.nhs.uk/ethnicity), including WMS Research Publications from 2004 to 2011 (<http://www2.warwick.ac.uk/fac/med/staffintranet/staffresources/researchpublications/&NoOfYears=5>). The reference lists of included studies and relevant review articles were screened for additional citations, and Google scholar searched for grey literature. Furthermore, two UK-based experts (in diabetes and EMGs (n=1), and diabetes and behavioural change research (n=1)) were contacted for advice and to identify additional studies. Diabetes and Primary Care Journal was hand searched as it was relevant to our topic but not accessible via Pub-Med or other major databases.

2.2.2. Inclusion criteria

The inclusion criteria were:

- Participants: Children or adults with any type of diabetes, provided they belong to an ethnic minority population in the country of study
- Design: Observational studies using qualitative or quantitative methods. RCTs and quasi-experimental studies were purposively excluded as they are included in the other review (Chapter Three).
- Setting: Participants were recruited from any setting
- Reporting: Studies were included if they reported on cultural differences and data extracted from themes that explored any cultural barriers
- Only primary published studies with no language restriction were applied.

The screening and mapping of the papers identified as a result of the search strategy (Table 2.1) highlighted two issues: cultural barriers preventing members of EMGs from accessing effective diabetes care services, which is the focus of this review; and culturally-competent healthcare interventions in EMGs with diabetes, which is presented in Chapter Three.

Table 2.1: Search Strategy

<p>Search terms</p> <p>Unless otherwise specified, search terms are free text terms; MeSH for Medical Subject Headings (CINAHL and MEDLINE medical index terms); exp = exploded MeSH; adj = adjacent; ti,ab = title, abstract; * = truncation</p>
<p><i>'Diabetes' search terms:</i></p> <p>exp DIABETES MELLITUS/ OR exp DIABETES MELLITUS, EXPERIMENTAL/ OR exp DIABETES MELLITUS, TYPE 2/; (diabet*2 adj2).ti,ab; NIDDM.ti,ab; T2DM.ti,ab; (gestational AND diabetes*).ti,ab; (Juvenile AND diabetes*).ti,ab; Diabet*1adj1.ti,ab; (Type AND 1 AND diabetes*).ti,ab; T1DM*.ti,ab; IDDM*.ti,ab; exp DIABETES MELLITUS/ OR exp DIABETES MELLITUS, TYPE 2/</p>
<p><i>"Cultural barriers" search terms:</i></p> <p>culture*.ti,ab; (cultural AND competent*).ti,ab; (language AND barrier*).ti,ab; exp COMMUNICATION BARRIERS/ OR exp INTERDISCIPLINARY COMMUNICATION/ OR exp NONVERBAL COMMUNICATION/ OR exp COMMUNICATION/ ; (NHS AND healthcare AND systems).ti,ab; (NHS AND health AND care AND systems).ti,ab; (delivery AND healthcare).ti,ab; exp HEALTH SERVICES ACCESSIBILITY/; exp CULTURAL DIVERSITY/ OR exp CULTURAL COMPETENCY/ OR exp HEALTH SERVICES ACCESSIBILITY/ OR exp NURSING STAFF/ ; (religious AND beliefs*).ti,ab; (cultural AND awareness*).ti,ab; (cultural AND characteristics*).ti,ab; multicultural*.ti,ab; transcultural*.ti,ab; crosscultural*.ti,ab</p>
<p><i>"Population" search terms:</i></p> <p>gujerat*.ti,ab; bengal*.ti,ab; exp ASIA, WESTERN/; exp INDIA/; bangladesh*.ti,ab; gujarat*.ti,ab; pakistan*.ti,ab; (south*adj2 AND asian*).ti,ab; ((south*adj2 indian*)).ti,ab; Punjab*.ti,ab; Urdu*.ti,ab; Hindi*.ti,ab; Hindu*.ti,ab; (African ADJ Caribbean).ti,ab; (ethnic AND minorities).ti,ab; (ethnic AND minority AND groups).ti,ab; human*.ti,ab</p>

2.2.3. Selection criteria

All citations were downloaded into Endnote Web and duplicates removed. All types of cultural and linguistic themes from any study involving any ethnic minority group with any type of diabetes in any setting globally were included. The titles/abstracts were independently scrutinised for eligibility by two reviewers [PZ (100% of all papers) and JS or HS (50% of the papers)] using the inclusion criteria and disagreements resolved through discussion and a third opinion (JS or HS or AMC). Cohen's Kappa was used to test the screening process inter-coder reliability and to calculate agreement levels. (Cohen, 1960) sets a threshold of 0.85 as representing a very high level of agreement, while Landis & Koch (1977) stipulate limits of greater than 0.61 as a substantial agreement and greater than 0.81 as a perfect agreement. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram details results of the screening and selection processes (Figure 2.1) (Moher *et al.*, 2009).

2.2.4. Data extraction and quality assessment of studies

One reviewer (PZ) read and re-read each of the full included publications to understand how the cultural barriers hindered the studied populations from accessing effective diabetes care services within the research settings and extracted data using a revised data extraction form by this researcher (see appendix 4), which included: study number, title, first author and year of publication, country of publication, aim of the study, participants' ethnicity and number, cultural theme, methodological details, content of the cultural issues, summary of findings, notes and follow-up questions for the authors. This form was piloted by three reviewers on three random included papers by cross-checking independent notes for consistency. The methodological quality of the qualitative studies was assessed using Popay *et al.* (1998) for qualitative studies, Jadad *et al.* (1996) for

quantitative, and Creswell and Plano Clark (2007) for the mixed method research studies. Individual quality assessment checklists, in contrast to a universal tool (Pluye *et al.*, 2009), were deemed more appropriate to facilitate specific study design assessments due to the heterogeneity of the included studies.

2.2.5. Data analysis

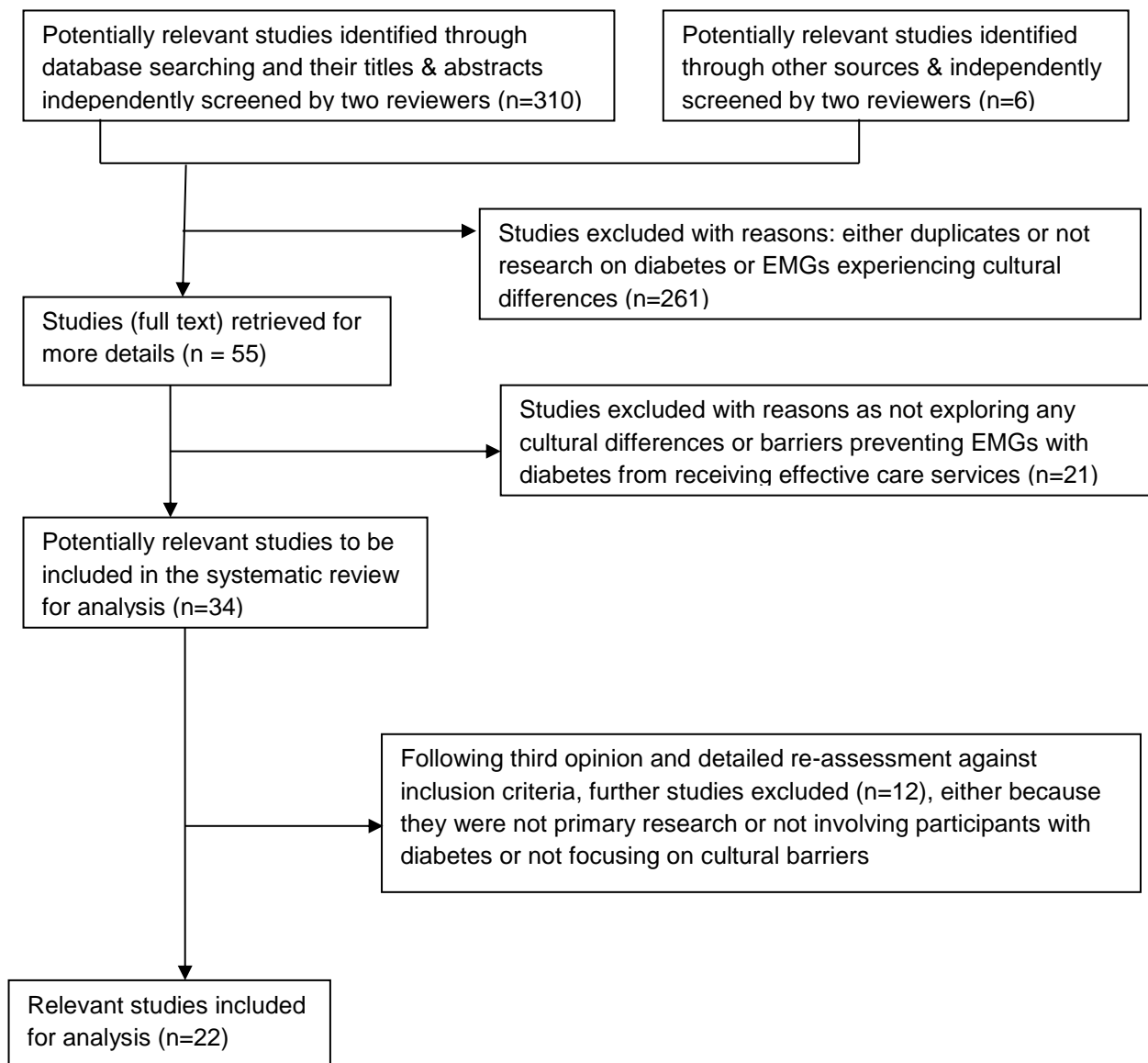
A narrative synthesis of the evidence was used because of the heterogeneity of the included studies. Following coding, thematic analysis was performed for each study and then tabulated across studies. Themes were discussed amongst all the researchers until agreement was reached. The results were combined without separating the included study designs (qualitative, quantitative or mixed-methods) to reduce duplication of themes and to improve validity and generalisability.

2.3. Results

2.3.1. Available evidence

The searches identified 316 studies (310 from databases and 6 from other sources) [figure 1] and from 55 potentially relevant studies (all in English), 22 were included (Table 2.2). The inter-coder reliability of the screening process was high (Kappa score of 0.92).

Figure 2.1: Flow chart (adapted from Moher et al. (2009) PRISMA) for screening and included studies on cultural barriers impeding ethnic minority groups from accessing effective diabetes care services



2.3.2. Characteristics of included studies

Of the 22 included studies (Table 2.2), 17 used qualitative methods (one mixed qualitative methods (Greenhalgh *et al.*, 1998), 12 in-depth interviews (Kelleher & Islam, 1994; Duthie-Nurse, 1998; Rhodes & Nocon, 2003; Rhodes *et al.*, 2003; Fagerli *et al.*, 2005; Hjelm *et al.*, 2005; Stone *et al.*, 2005; Lawton *et al.*, 2005; Lawton *et al.*, 2006b; Lawton *et al.*, 2006a; Lawton *et al.*, 2007a; Lawton *et al.*, 2008), 2 focus groups (Greenhalgh *et al.*, 2011; Brown *et al.*, 2006), and two used case study methods (Narayan & Rea, 1997; Fleming *et al.*, 2008). Two studies used mixed methods (Greenhalgh *et al.*, 2006; Lloyd *et al.*, 2008) and three used quantitative methods (Naeem, 2003; Sedgwick *et al.*, 2003; Povlsen *et al.*, 2005a). Studies were conducted in the UK (n=16), USA (n=2), Denmark (n=1), Sweden (n=1), Norway (n=1), and Netherlands (n=1). A total of 1,897 participants with varied ethnicities (see Table 2.3) were recruited from three settings (community, primary care and acute sectors). Nine studies included adults with type 2 diabetes (Greenhalgh *et al.*, 2006; Greenhalgh *et al.*, 2011; Fleming *et al.*, 2008; Lawton *et al.*, 2005; Lawton *et al.*, 2007b; Lloyd *et al.*, 2008; Kohinor *et al.*, 2011; Duthie-Nurse, 1998; Kelleher & Islam, 1994), two studies involved women with gestational diabetes (Narayan & Rea, 1997; Hjelm *et al.*, 2005), one included children with type 1 diabetes (Povlsen *et al.*, 2005a), four included participants with both type 1 and type 2 diabetes (Fagerli *et al.*, 2005; Stone *et al.*, 2005; Rhodes & Nocon, 2003; Rhodes *et al.*, 2003), five did not specify diabetes types (Brown *et al.*, 2006; Greenhalgh *et al.*, 1998; Naeem, 2003; Sedgwick *et al.*, 2003; Gonzalez, 2008). The characteristics, cultural and linguistic needs of these populations were varied. Participants' ages in all 22 studies ranged from 0 to 80 years.

2.3.3. Quality assessment of included studies and risk of bias

Of the 22 studies (Tables 2.4 to 2.6), fourteen studies were of good quality and met 80% to 100% of the quality criteria (scored A) [(Lloyd *et al.*, 2008; Greenhalgh *et al.*, 2006; Kohinor *et al.*, 2011; Greenhalgh *et al.*, 2011; Gonzalez, 2008; Lawton *et al.*, 2005; Lawton *et al.*, 2007b; Stone *et al.*, 2005; Hjelm *et al.*, 2005; Fagerli *et al.*, 2005; Rhodes & Nocon, 2003; Rhodes *et al.*, 2003; Chowdhury *et al.*, 2000; Greenhalgh *et al.*, 1998)]. A further 8 were of moderate quality and met 50% to 79% of quality criteria (scored B) [(Fleming *et al.*, 2008; Brown *et al.*, 2006; Duthie-Nurse, 1998; Narayan & Rea, 1997; Kelleher & Islam, 1994; Povlsen *et al.*, 2005a; Naeem, 2003; Sedgwick *et al.*, 2003)]. No study scored below 50%. Ten studies included participants from a range of EMGs; the group most strongly represented were black-Caribbean (n=522) in one UK study (Sedgwick *et al.*, 2003), the least common group was Lebanese (n=1) in one Swedish study which included twenty-seven participants from four ethnicities (Hjelm *et al.*, 2005). Of all the included studies, 73% (n=16) were published in the UK; USA (n=2); Denmark (n=1), Sweden (n=1), Norway (n=1) and Netherlands (n=1).

Table 2.2: Summary of included studies

References (first author & year)	Country of publication	EMG numbers studied	& numbers studied	Comparison	Design	Key cultural findings reported
Greenhalgh <i>et al.</i> (2011)	UK	82 adult participants (ACs (n=7), Bangladeshis (n=23), Tamil (n=11), Punjabi/Urdu (34), Somali (n=7)	Nil		Qualitative study based on narrative storey-sharing in groups	<ul style="list-style-type: none"> Strong attachment to social meaning and moral worth of real-life accounts of diabetes self-management Disapproval of shared facilities such as swimming pools (due to social/cultural beliefs of exposing their modesty) especially the Bangladeshi participants Strong adherence to religious beliefs (Muslim, Hindu, Sikh or Christian) with the perception that diabetes self-management is secondary Language barriers and unfamiliarity with the health care system (e.g. participants not aware of availability of interpretation or advocacy services) Low health literacy skills amongst participants, e.g. a lot of participants lacked knowledge and skills in diabetes complications and prevention Illness storylines affecting all life choices and decision makings (e.g. great stigma attached to diagnosis of diabetes and further augmented by going onto insulin, which caused participants to feel awful, frightened, isolated, and worthless to family or society) Strong adherence to fatalism (feeling of powerlessness against fate) at initial diagnosis of diabetes Reliance of older participants (especially women) on relatives in overseeing medication and operating technological devices or on health workers for those who did not have relatives to rely on.
Kohinor <i>et al.</i> (2011)	Netherlands	32 Surinamese adults (16 African Surinamese and 16 Hindustani Surinamese)	Nil		Qualitative study using in-depth interviews	<ul style="list-style-type: none"> Strong adherence to Surinamese traditional food even though participants were aware of the need to change their dietary behaviour in line with healthy dietary guidelines Strong adherence to cultural identity of traditional Surinamese cooking and eating practices Perception by many participants that dietary guidelines were based on Dutch eating habits, which are not in line with Surinamese cooking/eating practices Participants' food choices based on Surinamese beliefs regarding 'good' (e.g. bitter vegetables) or 'bad' (e.g. spicy dishes) foods for diabetes rather than basing them on their nutritional qualities Participants' perception of healthy recommendations (e.g. eating at fixed times) as interfering with their traditional values, such as hospitality.
Gonzalez (2008)	USA	12 Adult Puerto Ricans (Latinos) with diabetes recruited from	Nil		Narrative inquiry approach using semi-structured interviews in their	<ul style="list-style-type: none"> Participants' preference to ethnically and culturally concordant healthcare providers, e.g. one participant who received care from an ethnically discordant provider expressed feeling of being rushed - not being given time to express their feelings and issues of concern

		six sites in a South Florida city		preferred language [English (n=3), Spanish (n=8), and in both Spanish and English (n=1)]	<ul style="list-style-type: none"> • Participants' preference of linguistically-competent health-care providers, e.g. some participants voiced disappointment with the inability of service provider to meet their cultural needs due to language differences • Greater trust in the cultural-concordance Puerto Rican physicians for their diabetes care service delivery • Strong reliance of participants (11 out of 12) on family for support and guidance such as accompanying them to physician's offices to act as translators and/or acting as source of emotional and physical support • Religiosity and spirituality helping participants to cope with their diabetes but these two aspects did not influence their decision-making • Preference of Western medicines for the treatment of their diabetes even though aware of culturally-based ethno-medicine.
Lawton <i>et al.</i> (2005, 2006a, 2006b, 2008)	UK	32 adult South Asian patients with type 2 diabetes (Pakistanis (n=23) and Indians (n=9))	Nil	Qualitative study using in-depth interviews in participants' first language of English or Punjabi by a bilingual researcher	<ul style="list-style-type: none"> • Strong adherence to traditional diets/food (attachment to social and symbolic meanings) despite an awareness of their detrimental effects • Strong adherence to religious beliefs about food, fasting during Ramadan and attribute beliefs in Allah's will • Perceived cultural beliefs-notion that health, illness and death are pre-ordained by Allah and diabetes 'weakened and aged' the body (barrier to physical exercise and stigma associated with diabetes) • Strong adherence to cultural norms, e.g. family engagements; business, childcare come first, before their own interests • Perception that Western medicines have detrimental effects if taken in excess or without traditional foodstuffs, leading to self-adjusting without medical advice • Perception that oral hypoglycemic agents (Oral hypoglycaemic agents) give them an identity of a sick person, reflecting their unsure attitudes towards Western drugs • Strong attachment to commensal acts, and their need to eat 'strength-giving' South Asian foods; managing diet by cutting down on rather than replacing perceived risky South Asian foodstuffs • Inappropriate and/or conflicting information from health workers leading to non-concordance with dietary, medication and other healthcare advices • Lack of culturally sensitive single-sex facilities or same-sex instructors in gyms, swimming pools as well as culturally sensitive advice from white health workers with traditional dietary needs • Prefer receiving hospital reviews rather in primary care as perceived services for prompt detection and treatment of complications, rather than provision of advice on management • Language barriers leading to lack of diabetes knowledge reinforcing women vulnerability of the cultural norms of staying indoors • Low health literacy skills/level amongst participants • Gratefulness for the availability of free diabetes services in UK • Low perception of professional competency in India; health workers are money-minded in prescribing, giving preference treatments to

					their relatives.
Lawton <i>et al.</i> (2007)	UK	32 adult South Asian patients with type 2 diabetes (Pakistani and Indian)	32 White adult patients	Qualitative in-depth interviews	<ul style="list-style-type: none"> South Asian participants attributing the British weather and unfamiliar lifestyles and British values or past offences as responsible for their diabetes onset in particular whilst White British emphasizing the role of their own lifestyle (e.g. eating the wrong food, sedentary lifestyle) as responsible for their diabetes South Asian participants attributing life circumstances such as poverty, limited access to healthcare services and family-related stress as responsible for their diabetes onset generally whilst White participants associate their own lifestyle choices and personal lifestyle failings (e.g. non-adherence to healthy lifestyle and lack of self-discipline in diet and physical exercise) in their diabetes onset; portraying themselves, rather than their circumstances, as being to blame Some South Asian participants attributing their diabetes onset to the will of Allah who is responsible for dictating their health and destiny.
Greenhalgh <i>et al.</i> (2006)	UK	98 British Bangladeshi adults	Nil	Multi-phase study involving (a) narrative interview, (b) vignette construction, (c) questionnaire development, and (d) questionnaire validation in relation to two scales (well-being and cultural adherence)	<ul style="list-style-type: none"> Strict adherence to Bangladeshi culture, e.g. conserving their traditional dishes Low literacy level by participants Participants with language barrier needing assistance to complete questionnaires.
Rhodes & Nocon (2003)	UK	12 Bangladeshi adults	Nil	Qualitative in-depth interviews in English (n=1) & Bengali (n=11)	<ul style="list-style-type: none"> Very limited interpretation services resulting to communication difficulties between health workers and patients Use of informal interpreters a necessity due to limited professional interpreters resulting to both positive and negative effects Preference of same sex consultations especially females irrespective of language barrier Poor professional attitudes and methods of working especially doctors whose manners were described as 'abrupt and peremptory', resulting to dissatisfied consultations.
Chowdhury <i>et al.</i> (2000)	UK	40 first-generation immigrant Bangladeshi adults	Nil	Diverse qualitative methods involving interviews and focus group discussions conducted in their language (Sylheti)	<ul style="list-style-type: none"> Diverse range of individual food choices partly based on affordability and availability as well as cultural influences Strong adherence to religious restrictions on particular food items (e.g. Islamic prohibition of pork, wine or spirit) Food choices determined by two interrelated and intersecting binary classification systems: 'strong/weak' and 'digestible/indigestible' Conservation of cultural identity by adhering strictly to traditional

					diets/food (social and symbolic meanings) despite an awareness of detrimental effects
Duthie-Nurse (1998)	UK	20 first generation adult Hindu women of SA origin	Nil	Qualitative face-to-face questionnaire-based interview by researcher in the presence of a Gujarati-speaker	<ul style="list-style-type: none"> Strong adherence to traditional diets/food (social and symbolic meanings) despite an awareness of detrimental effects Strong adherence to their cultural identity such as social, religious and familial Language barriers reinforced women's vulnerability towards the cultural norms of staying indoors coupled with fear of racial harassment Perceived belief of being 'cured' when they go to India resulting to the association of illness with living in the UK rather than with their diet and physical inactivity.
Narayan & Rea (1997)	USA	1 Indian lady	Nil	Case study of an Indian lady with 34 weeks gestation, diagnosed with gestational diabetes	<ul style="list-style-type: none"> An experienced nurse failed to provide client's needs due to lack of knowledge of South Asian cultural beliefs and practices Nurse advice and dietary prescriptions contrarily to Indian Hindus tradition of not eating beef perceived as unacceptable and taboo! Participant's family not aware of nurse culture; feeling of humiliation and embarrassment as not involved in client's care planning.
Greenhalgh et al. (1998)	UK	40 first-generation immigrant Bangladeshi adults of male (n=23) & female (n=17) with diabetes	10 non-SA of Whites (n=8) & African Caribbean (n=2)	Qualitative using narratives, semi structured interviews, focus groups, structured vignette and pile sorting exercises conducted in Sylheti and English	<ul style="list-style-type: none"> Lay sources of information within Bangladeshi culture cited as key influence on behaviours; oral sources of information highly valued Strong adherence to religious views (Muslims); explanation given in terms of 'God's will' with the perception that adhering to dietary choices is the duty of the ill person Adherence to health beliefs, e.g. perception that diabetes is caused by Western lifestyle as it may be cured if returned to Bangladesh Language barriers and low literacy level even in their own Bengali language resulting to use of informal interpreters Food classifications not based on Western notions of nutritional content but in terms of perceived strength for nourishing powers Bangladeshis displayed more negative attitudes towards physical exercise, linked exercise to worsening their illness, women afraid to leave their homes because of physical harassments Perception by Bangladeshis that doctors know all about diabetes, but the other participants openly assertive and critical of health workers.
Kelleher & Islam (1994)	UK	20 Bangladeshi adults of male (n=12) and female (n=8)	Nil	Qualitative using in-depth interview, conducted in Sylheti dialect (n=18) and English (n=2)	<ul style="list-style-type: none"> Despite receiving dietary advice, still strong adherence to religion and traditional foods; fasting during Ramadan and perception that Western diets weaken them Religion seen as major influence for understanding illness and managing the treatment, explanation given in terms of 'God's will'- God is in front: doctor is behind Perception that even though with DM, God's orders must be adhered to, as disobeying them could lead to something worse.

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Fleming <i>et al.</i> (2008)	UK	5 English-speaking Gujarati Muslim men	Nil	Case-study approach using interviews and participant observation methods in English	<ul style="list-style-type: none"> Strong adherence to traditional foods with very high fat levels, fried foods (an integral part of Gujarati culture), with awareness of the detrimental effects Personal choice influenced by contextual factors such as the choice for allopathic or homeopathic medicines.
Lloyd <i>et al.</i> (2008)	UK	31 participants from 2 EMGs, both male and female whose main spoken language is Sylheti (n=16) & Mirpuri (n=15) concluded by 2 researchers fluent in English & either Sylheti or Mirpuri	Nil	5 focus groups of 5 sessions to consider the content & method of delivery 2 questionnaires measuring diabetes knowledge & confidence in diabetes self-care	<ul style="list-style-type: none"> Culturally-competent content successful for both questionnaires Particular terminology, such as HbA1c, carbohydrate and confidence, not universally understood, or have a single meaning/ interpretation Mirpuri participants' groups (Pakistanis) preferred assisted or partially assisted completion in their spoken language whilst Sylheti (Bangladeshi) groups' preference was for independent audio delivery in spoken language Low literacy level as more than half of Sylheti men and women were illiterates (59% for men & 62% for women).
Brown <i>et al.</i> (2006)	UK	39 adults with diabetes from multicultural EMGs	Nil	Qualitative using a participatory approach with consumer groups (6 focus groups)	<ul style="list-style-type: none"> Lack of cultural appropriate diabetes information for AC and SAs especially in their own language Lack of information on culturally-specific foods especially in restaurants and cafes AC and SAs valued one-to-one support from their health workers EMGs valued culturally & linguistically appropriate services; the need for bilingual health workers for direct communication Mixed perception about cultural beliefs with some participants feeling that they should take more responsibility for their condition and others denying the associated consequences of diabetes.
Stone <i>et al.</i> (2005)	UK	15 South Asian adults	5 White adults	Qualitative using semi-structured in-depth interviews in their preferred language of English (n=7), Gujarati (n=12) & Punjabi (n=1)	<ul style="list-style-type: none"> Most SA patients portrayed an attitude of resignation at diagnosis (family history or an expressed view that their diabetes is by God's will), whereas the Whites showed shock and at times in denial Strong adherence to traditional diets by SAs coupled with lack of specific dietary information as opposed to their White counterparts SAs expressing more health-related anxiety than white patients and supported more by families and religious leaders Cultural barriers, e.g. preference for gender specific education sessions but location & health problems are restrictive factors Communication problems including conflict messages expressed by both groups as health workers use technical terminology not understood by patients but SAs more language barriers .
Povlsen <i>et al.</i> (2005a)	Denmark	58 children	EMG 919 young	Danish Survey questionnaire	<ul style="list-style-type: none"> HbA1C significantly higher in EMGs (mean 9.05 +/- 1.4%) than the

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		participants	participants	about (gender, age, DM duration HbA1c, incidents of severe hypoglycaemia and ketoacidosis) from a national register to all 20 Danish paediatric diabetes centres & to 38 EMG families completed by professional interpreters	
Hjelm <i>et al.</i> (2005)	Sweden	14 Middle East women of which Iraqis (n=10), Iranians (n=3) & Lebanese (n=1)	13 Swedish-born women	qualitative, using in-depth semi-structured interviews conducted at week 34-38 of gestation in their first language using Arabic speaking interpreters when required	<p>Danish patients (mean 8.62 +/- 1.3%; P = 0.018)</p> <ul style="list-style-type: none"> No significant difference in HbA1C among the different EMGs, nor in the prevalence of severe hypoglycaemia or ketoacidosis Low literacy rate with limited educational backgrounds Language barriers amongst the EMGs and need for interpretation support.
Fagerli <i>et al.</i> (2005)	Norway	15 Pakistani adults	Nil	Qualitative in-depth interviews	<ul style="list-style-type: none"> Communication problems due to language barrier and use of concepts and terminology not understood by participants Lack of interpreters in consultations Non-availability of preferred traditional foods Professional advice generally perceived by participants as inadequate, leaving them to do the translation with different levels of knowledge.
Sedgwick <i>et al.</i> (2003)	UK	1,100 participants of Black Caribbean (n=522), Black African (n=163) & other EMGs (n= 415)	799 White participants	Questionnaire survey	<ul style="list-style-type: none"> No evidence that black African or black Caribbean people received less access to diabetes health care than their white counterparts in relation to their need, perhaps low quality due to language & cultural differences Need for interpretation support.
Rhodes <i>et al.</i> (2003)	UK	23 EMG participants of	22 White British	Qualitative in-depth interviews	<ul style="list-style-type: none"> Varied participants' experiences and their problems not solely attributed to cultural insensitivity by their providers' 'like it or lump it'

						<p>Bangladeshis (n=12), Pakistanis (n=14), Indians (n=4), Eastern Europeans (n=2) & West Indian (n=1)</p> <p>participants</p>		<p>approach</p> <ul style="list-style-type: none"> • Dissatisfaction by Bangladeshis with primary care due to lack of confidence in the doctors' competence, insufficient appointment systems, inappropriate information, lost files, failure of health workers to F/U missed appointments, difficulty to seeing doctor of choice • Perception of negative attitudes of doctors in primary care by Bangladeshis • Lack of professional language support resulting to limited choice leading to the use of informal support, not fully favoured • Low literacy level even in their Bengali language.
Naeem (2003)	UK	106	Muslim	Nil	Survey - face-to-face questionnaire with Kashmiri men completed by the researcher of their ethnic background who understood their culture and spoke the language as well			<ul style="list-style-type: none"> • Strong adherence to religious beliefs and practices; resulting to failure by participants to control and manage their condition; overall perceived attitude of enjoying life and "leave the rest to Allah • Strong adherence to cultural practices; influence of cultural values dominating their behaviour -traditional foods eating habits and etc • Participants' denial of being overweight; belief influenced by cultural norms in which the overweight figures tend to project prosperity and well-being in the community • Cultural practice of first cousin marriages; such cultural practices may lead to future hereditary complications.

Table 2.3: Ethnicity of ethnic minority groups

Bangladeshis	222
Black-Africans	163
Black-Caribbean	522
Eastern Europeans	2
Gujarati Muslims	5
Hindus	20
Indians	38
Iranians	3
Iraqis	10
Lebanese	1
Multicultural EMGs	543
Muslim Kashmiri	106
Pakistanis	121
Puerto Ricans	12
South Asians	15
Surinamese	32
Mixed ethnicity participants	82
Total	1,897

Table 2.4: Quality assessment for included qualitative research studies (Popay *et al.*, 1998)

Study References	Quality assessment criteria						%
	1	2	3	4	5	6	
Kohinor <i>et al.</i> (2011)	Yes	Yes	Yes	Yes	Yes	Can't tell	83.3% (A)
Greenhalgh <i>et al.</i> (2011)	Yes	Yes	Yes	Yes	Yes	Can't tell	83.3% (A)
Fleming <i>et al.</i> (2008)	Yes	Yes	Can't tell	Yes	Yes	Can't tell	66.7% (B)
Gonzalez (2008)	Yes	Yes	Yes	Yes	Yes	Can't tell	83.3% (A)
Lawton <i>et al.</i> (2007)	Yes	Yes	Yes	Yes	Yes	Can't tell	83.3% (A)
Brown <i>et al.</i> (2006)	Yes	Yes	Yes	Can't tell	Yes	Can't tell	66.7% (B)
Lawton <i>et al.</i> (2005, 2006a, 2006b, 2008)	Yes	Yes	Yes	Yes	Yes	Can't tell	83.3% (A)
Stone <i>et al.</i> (2005)	Yes	Yes	Yes	Yes	Yes	Can't tell	83.3% (A)
Hjelm <i>et al.</i> (2005)	Yes	Yes	Yes	Yes	Yes	Can't tell	83.3% (A)
Fagerli <i>et al.</i> (2005)	Yes	Yes	Yes	Yes	Yes	Can't tell	83.3% (A)
Rhodes <i>et al.</i> (2003)	Yes	Yes	Yes	Yes	Yes	Can't tell	83.3% (A)
Rhodes & Nocon (2003)	Yes	Yes	Yes	Yes	Yes	Can't tell	83.3% (A)
Chowdhury <i>et al.</i> (2000)	Yes	Yes	Yes	Yes	Yes	Can't tell	83.3% (A)
Duthie-Nurse (1998)	Yes	Yes	Can't tell	No	Yes	Can't tell	50% (B)
Greenhalgh <i>et al.</i> (1998)	Yes	Yes	Yes	Yes	Yes	Can't tell	83.3% (A)
Narayan <i>et al.</i> (1997)	Yes	No	Yes	Yes	Yes	Can't tell	66.7% (B)
Kelleher <i>et al.</i> (1994)	Yes	Yes	Can't tell	Yes	Yes	Can't tell	66.7% (B)

Questions relating to the quality criteria for assessment of qualitative research [(Popay *et al.*, 1998)]

- 1 A primary marker: Is the research aiming to explore the subjective meanings that people give to particular experiences of interventions?
- 2 Context sensitive: Has the research been designed in such a way as to enable it to be sensitive / flexible to changes occurring during the study?
- 3 Sampling strategy: Has the study sample been selected in a purposeful way shaped by theory and/or attention to the diverse contexts and meanings that the study is aiming to explore?
- 4 Data quality: Are different sources of knowledge / understanding about issues being explored compared?
- 5 Theoretical adequacy: Do the researchers make explicit the process by which they move from data to interpretation?
- 6 Generalisability: If claims are made to generalisability, do these follow logically and / or theoretically from the data?

NOTE: Each of the six criteria above answers 'yes' or 'no' or 'can't tell' and score at least 3/6 (50%) in order for the study to be included

Scoring classification of the quality of the included studies

- Good quality studies must answer 'yes' to 80%-100% of the quality assessment criteria and scored as 'A'
- Moderate quality studies must answer 'yes' to 50%-79% of the quality assessment criteria and scored as 'B'
- Weak quality studies must answer 'yes' to less than 50% of the quality assessment criteria and scored as 'C'

Table 2.5: Quality assessment for included quantitative studies (Jadad *et al.*, 1996)

			Quality assessment criteria												
Study References			1	2	3	4	5	6	7	8	9	10	11	%	
Povlsen	et	al.	No	No	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Yes	63.6% (B)	
(2005a)															
Naeem (2003)*			No	No	Yes*	Yes	Yes	Yes	No	Yes	No	No	No*	54.5% (B)	
Sedgwick	et	al.	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	72.7% (B)	
(2003)															

Questions relating to the quality criteria for assessment of the above studies

- 1 Was the study described as randomised?
 - 2 Was the study described as double-blind?
 - 3 Was there a description of withdrawals and drop outs?
 - 4 Were the objectives of the study defined?
 - 5 Were the outcome measures defined clearly?
 - 6 Was there a clear description of the inclusion and exclusion criteria?
 - 7 Was the sample size justified (e.g. power calculation)?
 - 8 Was there a clear description of the intervention?
 - 9 Was there at least one control (comparison) group?
 - 10 Was the method used to assess adverse effects described?
 - 11 Were the methods of statistical analysis described?
-

NOTE: Each of the eleven criteria above answers 'yes' or 'no' or 'can't tell' and score at least 6/11 (54.5%) in order for the study to be included

Scoring classification of the quality of the included studies

Good quality studies must answer 'yes' to 80%-100% of the quality assessment criteria and scored as 'A'

Moderate quality studies must answer 'yes' to 50%-79% of the quality assessment criteria and scored as 'B'

Weak quality studies must answer 'yes' to less than 50% of the quality assessment criteria and scored as 'C'

Table 2.6: Criteria for reporting and assessing mixed methods research (Creswell & Plano Clark, 2007)

Study References	Quality assessment criteria									%
	1	2	3	4	5	6	7	8	9	
Lloyd <i>et al.</i> (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	88.9% (A)
Greenhalgh <i>et al.</i> (2006)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	88.9% (A)

Quality criteria for assessment of the above mixed method studies (Creswell & Plano Clark, 2007)	
1	Description of qualitative, quantitative and mixed methods components
2	Literature review
3	Mixed methods design (triangulation, embedded, exploratory, explanatory)
4	Rigorous data collection and data analysis procedures
5	Validation of quantitative and qualitative data and/or results
6	Integration of quantitative and qualitative data and/or results
7	Interpretation of qualitative, quantitative and mixed evidence
8	Discussion of qualitative, quantitative and mixed methods limitations
9	Expertise in both quantitative and qualitative approaches

NOTE: Each of the nine criteria above answers 'yes' or 'no' or 'can't tell' and score at least 5/9 (55.6%) in order for the study to be included

Scoring classification of the quality of the included studies

Good quality studies must answer 'yes' to 80%-100% of the quality assessment criteria and scored as 'A'

Moderate quality studies must answer 'yes' to 50%-79% of the quality assessment criteria and scored as 'B'

Weak quality studies must answer 'yes' to less than 50% of the quality assessment criteria and scored as 'C'

2.3.4. Cultural barriers to diabetes care and management

Analysis of the included studies revealed eight themes related to cultural barriers to diabetes care and management:

- Cultural adherence to diet, exercise, and social interactions
- Commitment to religious beliefs
- Linguistic differences between patients and health workers
- Low health literacy levels
- Different beliefs about health and illness
- Belief in expert and professional support
- Low accessibility of culturally appropriate services/information
- Low concordance with Western professional advice

2.3.4.1. Cultural adherence to diet, exercise, and social interactions

Thirteen studies reported strict adherence to cultural norms (Kelleher & Islam, 1994; Narayan & Rea, 1997; Greenhalgh *et al.*, 1998; Chowdhury *et al.*, 2000; Naeem, 2003; Hjelm *et al.*, 2005; Lawton *et al.*, 2005; Stone *et al.*, 2005; Greenhalgh *et al.*, 2006; Lawton *et al.*, 2006a; Fleming *et al.*, 2008; Gonzalez, 2008; Lawton *et al.*, 2008; Greenhalgh *et al.*, 2011; Kohinor *et al.*, 2011). Participants in ten of these studies were of South Asian origins (Narayan & Rea, 1997; Kelleher & Islam, 1994; Lawton *et al.*, 2005; Lawton *et al.*, 2006a; Lawton *et al.*, 2008; Stone *et al.*, 2005; Chowdhury *et al.*, 2000; Greenhalgh *et al.*, 2011; Fleming *et al.*, 2008; Naeem, 2003; Greenhalgh *et al.*, 2006; Greenhalgh *et al.*, 1998). They had strong traditions relating to food, and their traditional dishes were generally high in fat or deep fried food despite awareness of their detrimental effects on health and wellbeing. Food classifications were based on the perceived strength of their nourishing powers rather than on Western notions of nutritional content. These strong

traditions and perceptions relating to food habits were similar in recent and older studies and contributed to the way these patients viewed diabetes services, in addition to diabetes self-management. Participants reported managing their diet by 'cutting down on' rather than replacing perceived risky foodstuffs (Lawton *et al.*, 2008). Food choices were determined by two interrelated and intersecting binary classifications - 'strong'/'weak' and 'digestible'/'indigestible,' which have social and symbolic meanings (Chowdhury *et al.*, 2000). Some participants perceived Western medicines as having detrimental effects if taken in excess or without eating traditional foodstuffs; this could lead to inappropriate self-adjustment of medication without medical consultation (Lawton *et al.*, 2005). Surinamese participants also reported strong traditions related to food, despite an awareness of the need to change their behaviour and adapt to healthy dietary guidelines (Kohinor *et al.*, 2011).

Regarding physical exercise, some participants of South Asian origins displayed more negative attitudes towards exercising, which they perceived to worsen their condition (Greenhalgh *et al.*, 1998; Lawton *et al.*, 2006a). Women reported more barriers to physical exercise: fear of physical harassment, gender norms, social rules and cultural expectations that women should be indoors. Diabetes 'weakened and aged' the body, which was reported as an additional barrier to undertaking physical exercise. Social interactions, traditional dishes at social and cultural events such as weddings and religious festivals were regarded as very important (Chowdhury *et al.*, 2000; Duthie-Nurse, 1998; Hjelm *et al.*, 2005; Lawton *et al.*, 2008); there was a strong attachment to social meanings and moral worth in real life accounts in diabetes self-management (Greenhalgh *et al.*, 2011).

2.3.4.2. Commitment to religious beliefs

Various religious beliefs (Muslim, Christian, Hindu and Sikh) and practices were prominent in 12 studies (Greenhalgh *et al.*, 1998; Kelleher & Islam, 1994; Duthie-Nurse, 1998; Hjelm *et al.*, 2005; Lawton *et al.*, 2005; Lawton *et al.*, 2006b; Lawton *et al.*, 2008; Greenhalgh *et al.*, 2011; Naeem, 2003; Kohinor *et al.*, 2011; Stone *et al.*, 2005; Gonzalez, 2008; Chowdhury *et al.*, 2000; Lawton *et al.*, 2007a). Eleven studies reported that participants, especially Muslims, demonstrated a strict commitment to religious beliefs about food and fasting during Ramadan, while diabetes self-management was a secondary consideration. All but one study (Lawton *et al.*, 2007a) identified religion and spirituality as a major influences on coping with/managing or understanding their diabetes. Religion was seen to support coping with anxiety in one study (Stone *et al.*, 2005).

Many studies (Greenhalgh *et al.*, 1998; Kelleher & Islam, 1994; Hjelm *et al.*, 2005; Greenhalgh *et al.*, 2011; Naeem, 2003; Stone *et al.*, 2005; Chowdhury *et al.*, 2000; Lawton *et al.*, 2007a) found that most Muslim and some Hindus and Sikh participants reported an external health locus of control (participant's belief about how much power they have over the events in their life). For example, Muslim participants reported that having diabetes was the will of Allah, beyond their control and as such accepted their fate. They generally attributed their beliefs and other behaviours to Allah's will, with the perception that adhering to dietary choices was the duty of an ill person. Whilst most participants were generally concerned about the impact of poor diabetes control, some Muslim participants had perceived attitude of 'enjoying life and leaving the rest to Allah,' resulting in poor diabetes control, especially during fasting periods (Naeem, 2003). In studies involving both ethnic minority and white European adults (Lawton *et al.*, 2007a; Hjelm *et al.*, 2005; Stone *et al.*, 2005), the ethnic minority participants (mostly Muslims)

showed resignation at the diagnosis of diabetes, citing family history or a view that it was Allah's will, whereas their white counterparts reacted with shock, denial and perceived consequences of diabetes complications.

2.3.4.3. Linguistic differences between patients and health workers

Fourteen studies attributed ineffective diabetes management to communication difficulties and lack of linguistically appropriate healthcare services (Greenhalgh *et al.*, 1998; Duthie-Nurse, 1998; Rhodes & Nocon, 2003; Rhodes *et al.*, 2003; Sedgwick *et al.*, 2003; Fagerli *et al.*, 2005; Hjelm *et al.*, 2005; Stone *et al.*, 2005; Lawton *et al.*, 2005; Lawton *et al.*, 2006b; Lawton *et al.*, 2006a; Brown *et al.*, 2006; Povlsen *et al.*, 2005a; Greenhalgh *et al.*, 2006; Gonzalez, 2008; Greenhalgh *et al.*, 2011). Five of these studies identified lack of knowledge about diabetes in EMGs arising from their inability to communicate in English (Greenhalgh *et al.*, 2011; Greenhalgh *et al.*, 1998; Hjelm *et al.*, 2005; Lawton *et al.*, 2005; Gonzalez, 2008). In three studies, participants preferred linguistically-competent healthcare providers to interpreters because they wanted communication to be direct and interpreters were perceived as a source of anxiety and frustration (Gonzalez, 2008; Brown *et al.*, 2006; Lawton *et al.*, 2006b). Two UK studies (Duthie-Nurse, 1998; Lawton *et al.*, 2006a) reported that linguistic barriers between participants and the public limited participants' knowledge of their neighbourhoods and reinforced their vulnerability and social isolation, which led to some participants (especially women) staying in-doors.

Seven studies identified a need for interpreter support (Greenhalgh *et al.*, 1998; Rhodes & Nocon, 2003; Rhodes *et al.*, 2003; Sedgwick *et al.*, 2003; Fagerli *et al.*, 2005; Povlsen *et al.*, 2005a; Greenhalgh *et al.*, 2011), with four reporting preference for professional interpreters instead of friends, relatives or receptionists (Rhodes & Nocon, 2003; Rhodes

et al., 2003; Sedgwick *et al.*, 2003; Fagerli *et al.*, 2005). Reliance on family members or friends to interpret was inconvenient; it disrupted people's routines and responsibilities. These participants also reported being uncomfortable discussing some aspects of their illness in front of their relatives/friends and preferred to 'die in silence (Rhodes & Nocon, 2003; Fagerli *et al.*, 2005).' Some participants were unaware of the availability of local interpretation or advocacy services (Greenhalgh *et al.*, 2011). Participants reported the use of medical jargon or technical terminology by health workers as a communication barrier (Fagerli *et al.*, 2005; Stone *et al.*, 2005; Lloyd *et al.*, 2008).

2.3.4.4. Low health literacy levels

Eight studies reported low health literacy skill levels, which were perceived by the specific populations as hindering them from receiving effective diabetes care services (Narayan & Rea, 1997; Greenhalgh *et al.*, 1998; Greenhalgh *et al.*, 2011; Rhodes *et al.*, 2003; Hjelm *et al.*, 2005; Lawton *et al.*, 2005; Lawton *et al.*, 2008; Povlsen *et al.*, 2005a; Gonzalez, 2008; Lloyd *et al.*, 2008). Some participants' lack of knowledge about diabetes was seen as a barrier to effective glycaemic control and/or diabetes self-management. For example, some participants only took their prescribed oral hypoglycaemic agents (OHAs) when their blood glucose levels were very high (over 18mmol/l) or omitted meals to avoid taking them (Lawton *et al.*, 2005).

In studies involving majority and minority populations, lower levels of educational attainment were reported within the minority groups, resulting in lower understanding of their diabetes (Rhodes *et al.*, 2003; Hjelm *et al.*, 2005; Povlsen *et al.*, 2005a). The severity of the literacy skills was noted in three studies (Greenhalgh *et al.*, 1998; Rhodes *et al.*, 2003; Lloyd *et al.*, 2008), where some of the ethnic minority participants could not read or

write in their first language. Audio-visual aids were used to improve comprehension, information retention, patient compliance and understanding if ethnic minority participants could not read or write in their first language. For some participants, lay and oral sources of health information were valued highly because of their low literacy skills (Greenhalgh *et al.*, 1998), while others were assisted by staff in their first language to complete research questionnaires (Greenhalgh *et al.*, 2006; Lloyd *et al.*, 2008). Lay diabetes information sources such as family or personal experiences appeared to have had a more profound influence on participants' behaviours rather than scientific evidence.

2.3.4.5. Beliefs about health and illness

Eleven studies reported various beliefs about health and illness based on religious, individual and societal factors as well as compromising healthcare service provision and/or concordance with professional advice or treatment (Lawton *et al.*, 2007; Greenhalgh *et al.*, 1998; Kelleher & Islam, 1994; Duthie-Nurse, 1998; Hjelm *et al.*, 2005; Lawton *et al.*, 2005; Lawton *et al.*, 2006a; Greenhalgh *et al.*, 2011; Brown *et al.*, 2006; Naeem, 2003; Stone *et al.*, 2005; Gonzalez, 2008). Muslim, Hindu and Sikh participants reported these factors as contributing to the way they perceived health and illness. Two sub-themes emerged in relation to perceived beliefs about health and illness: causation and integrating curative and diabetes self-management measures into everyday life.

2.3.4.5.1. Causation

Nine studies discussed perceived beliefs relating to the cause of diabetes (Lawton *et al.*, 2007a; Greenhalgh *et al.*, 1998; Kelleher & Islam, 1994; Duthie-Nurse, 1998; Hjelm *et al.*, 2005; Lawton *et al.*, 2006a; Greenhalgh *et al.*, 2011; Naeem, 2003; Stone *et al.*, 2005). These included hereditary, cold weather, unfamiliar Western lifestyles, stress, Allah's will and supernatural factors. Heredity meant that diabetes was unavoidable (Naeem, 2003;

Stone *et al.*, 2005). Attributing diabetes onset to 'Allah's will and beyond their control' was common amongst Muslim participants in six studies (Lawton *et al.*, 2007a; Kelleher & Islam, 1994; Hjelm *et al.*, 2005; Lawton *et al.*, 2006a; Naeem, 2003; Stone *et al.*, 2005), whereby health, destiny, illness and death were perceived to be pre-ordained by Allah. Five studies discussed the power of Allah beyond the individual patient's control, often leading to an attitude of resignation at diagnosis (Lawton *et al.*, 2007a; Hjelm *et al.*, 2005; Greenhalgh *et al.*, 2011; Naeem, 2003; Stone *et al.*, 2005). In one study (Hjelm *et al.*, 2005), involving ethnic minority and non-ethnic minority Swedish-born female participants, the non-ethnic minority Swedish-born participants attributed the cause of gestational diabetes to scientific explanatory concepts, feared developing Type 2 diabetes and sought medical help and advice from healthcare professionals. Their beliefs about health and illness were explained in medical terms. Ethnic minority participants attributed the onset of diabetes to social and supernatural factors, which made them reluctant to seek medical advice. In another study, South Asian participants attributed diabetes onset to British lifestyles/values or as a form of punishment for their past religious sins; other life circumstances such as poverty, limited access to healthcare services and family-related stress were also regarded as causes of diabetes. In contrast, white British participants considered their own lifestyle choices and personal failings, thus adopting an internal locus of control (Lawton *et al.*, 2007a).

Five studies reported diet and/or lifestyle as contributing factors to developing diabetes (Greenhalgh *et al.*, 1998; Naeem, 2003; Hjelm *et al.*, 2005; Brown *et al.*, 2006; Lawton *et al.*, 2006a) with one aligning 'overweight figures' to the cultural norms of projecting prosperity and well-being in the community rather than a health risk (Naeem, 2003). In two of these studies participants partially associated physical exercise with diabetes, linking

physical exercise to worsening of their condition (Greenhalgh *et al.*, 1998; Lawton *et al.*, 2006a). South Asian participants linked cold weather rather than diet and/or inactivity to the onset of their diabetes and believed returning to South Asia would 'cure' them (Duthie-Nurse, 1998; Greenhalgh *et al.*, 1998).

2.3.4.5.2. Integrating curative and diabetes self-management measures into everyday life

This subtheme examines the perceived healing paradigms and beliefs about diabetes self-management. In total, eleven studies (Lawton *et al.*, 2007; Greenhalgh *et al.*, 1998; Kelleher & Islam, 1994; Duthie-Nurse, 1998; Hjelm *et al.*, 2005; Lawton *et al.*, 2005; Lawton *et al.*, 2006a; Greenhalgh *et al.*, 2011; Brown *et al.*, 2006; Naeem, 2003; Stone *et al.*, 2005; Gonzalez, 2008) reported at least one aspect of diabetes self-management, which demonstrated participants' perception about diabetes and their daily coping mechanisms. In ten of these studies, participants acknowledged that diabetes was a permanent condition and could be controlled, to an extent, through natural or supernatural and/or medicinal means. For example, in Lawton *et al.*, participants reported that if Western medicines were taken in excess, they could cause side effects, worsening their condition (Lawton *et al.*, 2005). Additionally, they perceived traditional diets like chapatti and curry as having strengthening properties to counterbalance these side effects of medication. In another study (Lawton *et al.*, 2008), participants acknowledged the detrimental effects on their blood glucose control of some South Asian foodstuffs, such as roti (complete meal of curry, chapatti and/or rice with side dishes), yet most (especially first generation) did not effect dietary changes.

Participants also expressed initial qualms about taking oral hypoglycaemic agents for fear of acquiring the 'sick person's identity' (Lawton *et al.*, 2005). In one study, Gujarati Muslim

men believed in the healing powers of allopathic medicine and other complementary therapies, especially herbal therapies (Fleming *et al.*, 2008), whilst in another, the Puerto Rican participants preferred and perceived better effects from Western medicines as opposed to complementary and alternative medicines (Gonzalez, 2008).

2.3.4.6. Belief in expert and professional support

In seven studies, some participants expressed reduced confidence in health workers, questioned their competence and the support they offered (Narayan & Rea, 1997; Greenhalgh *et al.*, 1998; Lawton *et al.*, 2005; Lawton *et al.*, 2006b; Rhodes & Nocon, 2003; Rhodes *et al.*, 2003; Brown *et al.*, 2006; Gonzalez, 2008). Participants in three of these studies had confidence in British doctors and perceived them to be competent and trustworthy. In contrast, Indian subcontinent doctors were perceived as untrustworthy, lacking training and sometimes giving preferential treatment to the wealthy, relatives and friends (Lawton *et al.*, 2005; Lawton *et al.*, 2006b; Rhodes & Nocon, 2003; Rhodes *et al.*, 2003). One of these studies reported that medicines available in Britain were superior but inherently dangerous as compared to those available from the Indian subcontinent (Lawton *et al.*, 2005), whilst another perceived the purpose of healthcare services to be for prompt detection and treatment of complications, rather than the provision of advice about managing their condition (Lawton *et al.*, 2006b).

In one study (Narayan & Rea, 1997), family members of a Hindu patient with gestational diabetes felt humiliated and embarrassed following their exclusion from her care planning. They saw it as contrary to their customs of involving family members and valuing their contribution to care. In two studies involving African-Caribbean and South Asians (Brown

et al., 2006) and Puerto Ricans (Gonzalez, 2008), participants valued one-to-one linguistically and culturally-concordant support from their health workers.

2.3.4.7. Low accessibility of culturally appropriate services and information

Nine studies reported variations in participants' experiences with negative issues relating to accessing culturally appropriate services or information (Narayan & Rea, 1997; Greenhalgh *et al.*, 1998; Greenhalgh *et al.*, 2011; Rhodes & Nocon, 2003; Rhodes *et al.*, 2003; Stone *et al.*, 2005; Brown *et al.*, 2006; Lawton *et al.*, 2006b; Lawton *et al.*, 2006a; Lawton *et al.*, 2008; Kohinor *et al.*, 2011). Gender issues, lack of culturally sensitive facilities during clinical consultations and preferences for same sex health workers irrespective of language barriers were reported by some participants as a contributory factor for not accessing effective diabetes care services (Rhodes & Nocon, 2003). Some women avoided mixed-sex leisure facilities such as swimming pools or male gym instructors (Rhodes & Nocon, 2003; Lawton *et al.*, 2006a), due to social and cultural beliefs about modesty (Greenhalgh *et al.*, 2011). Six studies reported inappropriate and/or lack of culturally appropriate diabetes (and sometimes conflicting) information on diet/foods from health workers (Greenhalgh *et al.*, 1998; Narayan & Rea, 1997; Stone *et al.*, 2005; Brown *et al.*, 2006; Lawton *et al.*, 2008; Kohinor *et al.*, 2011), with participants in one study (Stone *et al.*, 2005) particularly expressing preference for gender specific diabetes education sessions. Participants in two studies reported having received inappropriate information from healthcare workers leading to non-concordance with dietary and other healthcare advices (Greenhalgh *et al.*, 1998; Rhodes *et al.*, 2003). For instance, some Bangladeshi participants reported receiving leaflets in Bengali despite having very limited literacy skills (Rhodes *et al.*, 2003). Another two studies, reported culturally-insensitive advice (Narayan & Rea, 1997; Lawton *et al.*, 2006b). for example, a

Hindu patient was prescribed beef, perceived by Hindus as taboo, which contributed to the patient's non-concordance with the care package recommended by the nurse (Narayan & Rea, 1997).

2.3.4.8. Low concordance with Western professional advice

Eleven studies reported that participants did not follow professional advice due to lack of cultural knowledge, religious and language differences, or contextual factors, which were sometimes miss-interpreted by health workers (Kelleher & Islam, 1994; Narayan & Rea, 1997; Duthie-Nurse, 1998; Chowdhury *et al.*, 2000; Naeem, 2003; Hjelm *et al.*, 2005; Lawton *et al.*, 2005; Lawton *et al.*, 2008; Stone *et al.*, 2005; Fleming *et al.*, 2008; Greenhalgh *et al.*, 2011; Kohinor *et al.*, 2011). Participants expressed a desire for dietary balance but reported the importance of the traditional norms and beliefs about their foods, which some claimed made them 'weak and not strong enough' (Kelleher & Islam, 1994; Duthie-Nurse, 1998; Chowdhury *et al.*, 2000; Lawton *et al.*, 2008; Fleming *et al.*, 2008). All these factors contributed to their non-adherence to the professional recommended diet. Two studies reported conflicting professional dietary advice and prescriptions that were contrary to participants' traditions (Narayan & Rea, 1997; Kohinor *et al.*, 2011). Furthermore, one of the aforementioned two studies reported healthcare professionals' lack of cultural awareness resulting in a mis-match between prescribed interventions and the patient's beliefs and values (Narayan & Rea, 1997).

In one study, participants reported deliberately reducing their tablet intake without medical advice and concordance only when they were lethargic or unwell and despite awareness of the importance of prescribed oral hypoglycaemic agents (Lawton *et al.*, 2005). In another study (Fleming *et al.*, 2008), Gujarati Muslim men noted that contextual factors such as the choice for allopathic or cheaper homeopathic medicines influenced their

choices, whereby they sometimes chose the latter as they are cheaper. Stigma associated with having diabetes was reported as a factor contributing to low concordance with professional advice by some participants (Lawton *et al.*, 2007a; Lawton *et al.*, 2006a; Greenhalgh *et al.*, 2011).

2.4. Discussion

2.4.1. Discussion of key findings

This was a systematic review which integrated qualitative, quantitative and mixed-methods study designs to maximise the research findings based on the research questions (Harden, 2010). The themes identified from this review of different ethnic, cultural and religious groups are participants' strong adherence to culture, religious beliefs, linguistic differences between them and their health workers, low health literacy levels, different beliefs about health and illness, belief in expert and professional support, low accessibility of culturally appropriate services/information and low concordance with Western professional advice. Although we are not claiming that our findings are universal, our review has collated and demonstrated significant cultural and linguistic barriers, perceived by members of EMGs as compromising diabetes care. There appeared to be gaps in identifying and making adjustments to meet specific needs which could enhance the engagement of members of EMGs, increase their personal satisfaction with diabetes service provision and, ultimately, improve their health-related outcomes. For instance, only three studies (Lawton *et al.*, 2006b; Sedgwick *et al.*, 2003; Brown *et al.*, 2006) reported specific attempts to seek their opinions on services or their cultural needs, basing their needs instead on the authors' perceived interpretations. In line with previous recommendations (Goody & Drago, 2009; Brown *et al.*, 2002; Hill, 2006), more work is required to improve cultural competences amongst health workers to enable them to more

effectively empower patients to self-manage their diabetes. Health policies should be directed towards improving cultural competence training to facilitate partnership working between patients and their health care providers. This has been shown to improve professional skills, cultural knowledge and attitudes amongst health care professionals enabling them to work effectively in cross-cultural situations, thereby yielding positive health-related outcomes for their ethnic minority patients (Majumdar *et al.*, 2004; Khanna *et al.*, 2009).

For people with diabetes, knowledge of diabetes can significantly predict their perceptions of the quality of services they receive and their own illness perceptions (Baradaran & Knill Jones, 2004). The inability of members of EMGs to speak English fluently and low health literacy in their own mother tongue are seen, in the UK context, as contributing factors to increasing social distance, reducing communication, which often threatens trust between patients and their health workers (Commission., 2000; Greenhalgh *et al.*, 2011). Appropriate linguistically-competent tools have been proposed to provide high quality diabetes care services to EMGs (Roy & Lloyd, 2008).

Culture is an on-going social and dynamic phenomenon displayed by the behaviours and attitudes of a social group, which remains difficult to measure, but requires a good understanding by health workers (Naeem, 2003). Therefore, caution should be taken in interpreting these results due to the heterogeneity of the studies including factors such as place of publication, recruitment settings, designs, studied populations, and explored cultural differences. Seventy-three percent (n=16) of the included studies were published in the UK, which has significant numbers of ethnic minorities with diabetes. Therefore, this review may be more applicable to the UK primary care situation.

Participants' non-concordance with professional advice regarding diet, medications, lifestyle modifications and their adherence to traditional values, especially food highlight an integral part of social identity for most ethnic minorities (Lawton *et al.*, 2007a; Mellin-Olsen & Wandel, 2005). Some studies reported the "cutting down" of perceived risky foodstuffs, which may require behavioural interventions. Health workers need to acknowledge cultural similarities and differences and build trust that might encourage concordance (Goody & Drago, 2009). Dietary advice and information should not be prescriptive but negotiated, affordable, culturally sensitive, and take account of the importance of food in the individual patient's ethnic and social context as well as their religious, cultural and health and illness beliefs (Brown, 1997; Hill, 2006). Diabetes health workers need to possess culturally-competent knowledge in different cultures and ethnic foods, to empower these people to practise healthy lifestyles rather than to abandon familiar foods, as the evidence from the included studies illustrated limited cultural competences in these areas.

2.4.2. Strengths and limitations of the review

The search criteria included all EMGs with all types of diabetes and all primary qualitative and quantitative studies, excluding RCTs and quasi-experimental studies (reported in Chapter Three), which explored cultural differences globally. The quality of studies was assessed and any research design included to uncover any relevant studies that have explored cultural differences in diabetes. Combining the results from the three included designs (quantitative, qualitative and multi-methods) was a strength as this could potentially improve validity and generalisability. Our design was rigorous, compared with previous systematic reviews that limited their search to specific EMGs, study types or

specific types of diabetes and which did not formally assess the methodological quality of included studies (Brown *et al.*, 2002; Fleming & Gillibrand, 2009).

Limitations of this review include the heterogeneity of studies, resulting in difficulties in analysing the results or drawing conclusive views. Some current research involving Eastern European populations within the UK may have been excluded as only published studies were included. Excluding RCTs and quasi-experimental studies in this review, the researchers may have missed some important information about EMGs, such as exploring different aspects of cultural barriers and reporting on their effectiveness. However, our aim was to collate and highlight these barriers in order to target appropriate interventions for EMGs with diabetes. Chapter Three identified the key elements for such interventions. Furthermore, some cultural barriers may be specific to certain EMGs. Grouping all EMGs together may be contentious as they may differ, in terms of health patterns and the effects of interventions, making it difficult to provide generic recommendations. In fact, the definitions of EMGs, culture and cultural barriers have been restricted in this review, as they have diverse interpretations. The fact that not all studies included participants' health literacy levels may pose training and comprehension issues, and it is difficult to ascertain if specific cultural barriers pertained to specific ethnic groups and/or age groups, which may require different educational needs. In addition, other evidence about EMGs may have been missed by excluding other chronic conditions such as cancer.

2.4.3. Conclusions, implications for practice and recommendations for further research

This review examined cultural barriers that can affect the quality of life of EMGs with diabetes and their glycaemic control, including communication problems, religion, health literacy skill levels and beliefs about health and illness. Understanding these issues may

enable health workers to deliver culturally-appropriate and individualised care and thus reduce health inequalities in diabetes service provision. The review examined the cultural issues and offers suggestions to guide the planning and commissioning of culturally appropriate diabetes services for ethnic minority populations. Sustained and targeted actions by health commissioners and partnership with all stakeholders in diabetes management (local authorities, community organisations, primary and secondary care diabetes leads, clinical commissioning group leaders, academic institutions, carers and service users) are essential in improving diabetes-related outcomes of the affected populations.

To minimise cultural barriers and improve care and management tailored to the needs of EMGs, our recommendations are to:

1. Use the eight themes identified in this review in informing healthcare professional training curricula to develop and deliver culturally-competent diabetes services;
2. Provide culturally-competent training to diabetes health educators who will support the development and implementation of specific community-based interventions, to help newly diagnosed patients come to terms with their condition and facilitate their navigations through healthcare systems (Greenhalgh *et al.*, 2011);
3. Target recruitment and training of multilingual health care professionals to improve their knowledge of diabetes and health literacy;
4. Minimise the use of medical jargon or technical terminology and ensure continuous assessment of patients' understanding during clinical engagements;
5. Develop psychological and behavioural interventions to enable individuals to take responsibility for their diabetes self-management;

6. Acknowledge the influence of dominant and minority cultures on concordance and seek to influence those aspects perceived to be changeable by the patient through patient-centred education;
7. Design future research to investigate the effectiveness of community-led interpersonal health information sources/centres, including written and audiovisual materials associated with ethnic minority populations' cultural beliefs;
8. Design randomised controlled trials around the themes identified from this review to test out interventions, which should include the participation of the ethnic minority populations;
9. Qualitatively explore health workers' perceptions and understanding of ethnic minority peoples' eating patterns (and why), and how these might guide the advice given to patients. This might clarify the perceptions about South Asian foods, and establish if health workers themselves hold incorrect or stereotypical perceptions.

CHAPTER THREE

THE IMPACT OF CULTURALLY-COMPETENT DIABETES CARE INTERVENTIONS FOR IMPROVING DIABETES-RELATED OUTCOMES IN ETHNIC MINORITY GROUPS: A SYSTEMATIC REVIEW

Zeh, P., Sandhu, H. K., Cannaby, A. M., Sturt, J. A. (2012). *Diabetic Medicine*; 29(10):1237-52.

3.0. Abstract

Aim: To examine the evidence on culturally-competent interventions tailored to the needs of people with diabetes from ethnic minority groups.

Methods: Medline (NHS Evidence), CINAHL and reference lists of retrieved papers were searched from inception to September 2011 and two NHS specialist libraries were also searched. Google, Cochrane and DARE databases were interrogated, and experts consulted. Studies were included if they reported primary research on the impact of culturally-competent interventions on outcome measures of any ethnic minority group with diabetes. Paper selection and appraisal were conducted independently by two reviewers. The heterogeneity of the studies required narrative analysis. A novel culturally-competent assessment tool (CCAT) was used to systematically assess the cultural competency of each intervention.

Results: Three hundred and twenty papers were retrieved and 11 included. Study designs varied with a diverse range of service providers. Of the interventions, 64% were found to be highly culturally-competent (scoring 90%-100%), and 36% moderately culturally-competent (70%-89%). Data were collected from 2616 participants on 22 patient reported outcome measures. A consistent finding from 10 of the studies was that: any structured intervention, tailored to EMGs by integrating elements of culture, language, religion, and health literacy skills, produced a positive impact on a range of patient important outcomes.

Conclusions: Benefits in using culturally-competent interventions with EMGs with diabetes were identified. The majority of interventions described as culturally-competent were confirmed as so, when assessed using the CCAT. Further good quality research is required to determine effectiveness and cost-effectiveness of culturally-competent interventions to influence diabetes service commissioners.

3.1. Introduction

The burden of diabetes disproportionately falls on EMGs who recurrently experience higher morbidity and mortality than majority populations due to complex cultural, physiological and linguistic reasons (Griffiths *et al.*, 2005; Alexander *et al.*, 2008; Zeh, 2010; Amos *et al.*, 1997). These groups do not always receive adequate diabetes care due to barriers such as linguistic difference, limited educational backgrounds, and religious, health and illness beliefs that are not familiar to the majority population; thus predisposing them as vulnerable groups within their host country health care systems (Povlsen *et al.*, 2005). Some authors have argued that the provision of appropriate interventions by culturally-and linguistically-competent healthcare professionals (HCPs) can confer important benefits, not only on people with diabetes and their families but can also bring about cost savings in every nation's healthcare system (Wolf *et al.*, 2007).

As in Chapter Two, EMGs are defined as a population group with an ethnic origin different from that of the majority population of the host country (Bulmer, 1996; Modood & Berthoud, 1997). Cultural competence in healthcare service delivery is present when *'individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions, and other diversity factors in a manner that recognises, affirms, and values the worth of individuals, families, and communities and protects and preserves the dignity of each'* (Mizrahi *et al.*, 2001). For health interventions, defined broadly as care or services delivered to people in a healthcare or research setting, to be culturally-competent and successfully implemented by cultural groups, healthcare workers need an awareness of cultural differences and are required to deliver healthcare services in an effective and compassionate manner, maximising sensitivity and taking into account the patients' cultural beliefs, behaviours and

needs (Papadopoulos *et al.*, 2004). This is because each culturally diverse group defines health and illness differently (Hjelm *et al.*, 2005; Fleming & Gillibrand, 2009).

Five previous systematic reviews focused on reviewing culturally-competent education interventions in EMGs with diabetes and reported varied effects in health-related outcomes (Saxena *et al.*, 2007; Whittemore, 2007; Alam *et al.*, 2008; Khunti *et al.*, 2008; Hawthorne *et al.*, 2010). These reviews found that structured diabetes education programmes are central to effective diabetes self-management (Alam *et al.*, 2008; Khunti *et al.*, 2008). Culturally-competent health education and case management models have some benefits over 'usual' care in improving glycaemic control and/or diabetes knowledge but their long-term effects and sustainability on patient-centred and clinical outcomes are unknown (Saxena *et al.*, 2007; Hawthorne *et al.*, 2010). Furthermore, another review suggested that diabetes self-management interventions effective in the general population, when modified to be culturally-competent, can improve health-related outcomes in EMGs (Whittemore, 2007). However, little is known about (a) what components and implementation process constitutes a culturally-competent intervention and (b) what is the impact of culturally-competent interventions for ethnic minority populations with diabetes (Khunti *et al.*, 2008; Hawthorne *et al.*, 2010).

3.2. Methods

3.2.1. Eligibility

Studies were eligible for inclusion if they reported primary research on the impact of culturally-competent interventions on any outcome measures to any ethnic minority population within a majority population globally with any type of diabetes. No publication

date or language restrictions were employed. Studies were excluded, when they did not focus on an ethnic minority group within a majority population.

3.2.2. Search strategy

The search strategy (Table 3.1) aimed to identify all references to diabetes, cultural competence and EMGs. The following databases were used from inception to September 2011: CINAHL and MEDLINE (NHS Evidence). In addition, searches using MeSH and key words were conducted using: Cochrane and DARE databases, the two NHS specialist libraries hosted at Warwick University for ethnicity and health (www.library.nhs.uk/ethnicity) and diabetes (www.library.nhs.uk/diabetes), including the Warwick Medical School (WMS) Research Publications from 2004 to 2011 (<http://www2.warwick.ac.uk/fac/med/staffintranet/staffresources/researchpublications/&NoOfYears=5>). The reference lists of included studies and relevant review articles were screened for additional citations, and Google Scholar searched for grey literature. Four UK-based experts were consulted: in diabetes and EMGs (n=1), diabetes and cultural-competence (n=2), and cultural-competences (n=1) to identify additional studies, and Google hand searches for any relevant papers written by three of these experts.

Table 3.1: Search strategy

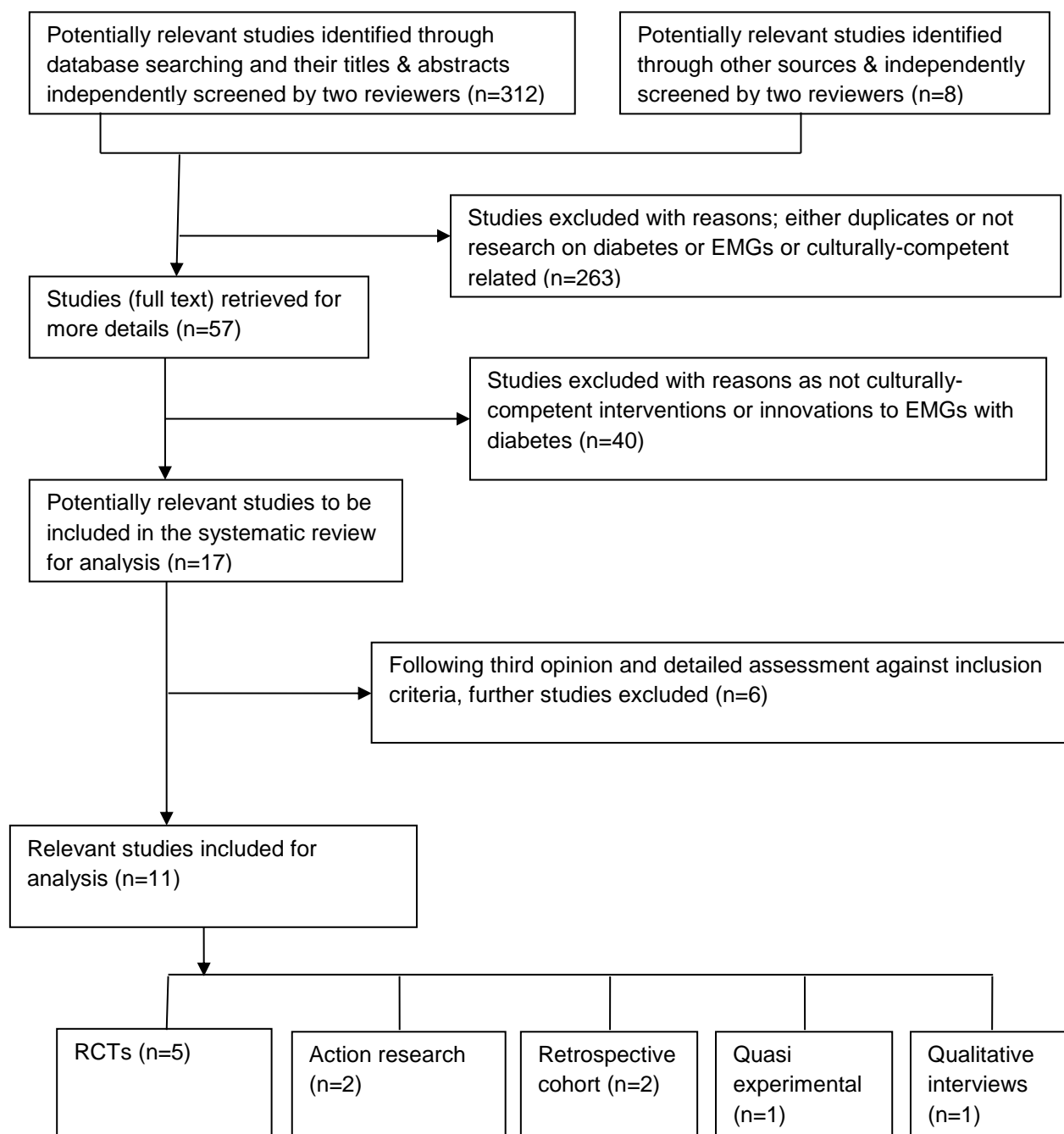
<p>Search terms</p> <p>Unless otherwise specified, search terms are free text terms; MeSH for Medical Subject Headings (CINAHL and MEDLINE medical index terms); exp = exploded MeSH; adj = adjacent; ti,ab = title, abstract; * = truncation</p>
<p>‘Diabetes’ search terms:</p> <p>exp DIABETES MELLITUS/ OR exp DIABETES MELLITUS, EXPERIMENTAL/ OR exp DIABETES MELLITUS, TYPE 2/; (diabet*2 adj2).ti,ab; NIDDM.ti,ab; T2DM.ti,ab; (gestational AND diabetes*).ti,ab; (Juvenile AND diabetes*).ti,ab; Diabet*1adj1.ti,ab; (Type AND 1 AND diabetes*).ti,ab; T1DM*.ti,ab; IDDM*.ti,ab; exp DIABETES MELLITUS/ OR exp DIABETES MELLITUS, TYPE 2/</p>
<p>“Cultural competence” search terms:</p> <p>culture*.ti,ab; (cultural AND competent*).ti,ab; (language AND barrier*).ti,ab; exp COMMUNICATION BARRIERS/ OR exp INTERDISCIPLINARY COMMUNICATION/ OR exp NONVERBAL COMMUNICATION/ OR exp COMMUNICATION/ ; (NHS AND healthcare AND systems).ti,ab; (NHS AND health AND care AND systems).ti,ab; (delivery AND healthcare).ti,ab; exp HEALTH SERVICES ACCESSIBILITY/; exp CULTURAL DIVERSITY/ OR exp CULTURAL COMPETENCY/ OR exp HEALTH SERVICES ACCESSIBILITY/ OR exp NURSING STAFF/ ; (religious AND beliefs*).ti,ab; (cultural AND awareness*).ti,ab; (cultural AND characteristics*).ti,ab; multicultural*.ti,ab; transcultural*.ti,ab; crosscultural*.ti,ab</p>
<p>“Population” search terms:</p> <p>gujerat*.ti,ab; bengal*.ti,ab; exp ASIA, WESTERN/; exp INDIA/; bangladesh*.ti,ab; gujarat*.ti,ab; pakistan*.ti,ab; (south*adj2 AND asian*).ti,ab; ((south*adj2 indian*).ti,ab; Punjab*.ti,ab; Urdu*.ti,ab; Hindi*.ti,ab; Hindu*.ti,ab; (African ADJ Caribbean).ti,ab; (ethnic AND minorities).ti,ab; (ethnic AND minority AND groups).ti,ab; human*.ti,ab</p>

3.2.3. Selection criteria

Abstracts were independently screened for eligibility by two reviewers, and disagreements resolved through discussion and consensus or third opinion. Agreement level was calculated using Cohen’s Kappa to test the inter-coder reliability of this screening process.

The PRISMA flow diagram (Figure 3.1) shows the detailed results of the screening and selection process (Moher *et al.*, 2009).

Figure 3.1: Flow chart (adapted from Moher *et al.* (2009) PRISMA) of screening and included studies



3.2.4. Development of a culturally-competent assessment tool for assessing health interventions

Literature searches and consultation with experts were undertaken to identify tools for assessing cultural competence of interventions, but no existing tools were identified. Papadopoulos et al.'s (1998) Model for the 'Development of Transcultural Competence' was therefore used as a basis to develop a tool to test the cultural competency of healthcare delivery interventions. The newly developed Culturally-Competent Assessment Tool (CCAT) (Table 3.2), includes ten culturally-competent criteria to systematically determine cultural competence, and was applied to the interventions identified in the systematic review led by PZ.

The research team consisted of six members (three members belonging to a minority group and three were White British Caucasians). All members had expertise in healthcare provision to EMGs with diabetes. Three of the members had senior nursing experience, of whom one was an expert in behavioural medicine and management in long-term conditions, two members were health psychologists specialising in behaviour change interventions and one team member was a consultant physician in diabetes and endocrinology with vast experience of developing and delivering culturally-competent interventions to EMGs with diabetes.

Over six monthly meetings, the research team members used their experiences along with other resources [components of the Papadopoulos et al.'s (1998) Model (Box 3.1); Hawthorne and Tomlinson 1997; Mehler et al, 2004; Joshi et al., 2010; Khana et al., 2009; Hawthorne et al., 2010, Khunti et al., 2008; Greenhalgh et al., 1998; Greenhalgh et al., 2005; Greenhalgh et al., 2008; Lloyd et al., 2008)], to initially formulate criteria 1-9 (see

Table 3.2). The Papadopoulos et al.'s (1998) Model directly (Box 3.1) contributed to CCAT criteria 2,3,4,8 and 9. Box 3.1 shows which elements were drawn upon to develop these CCAT criteria. A number of authors (Mehler et al, 2004; Hawthorne et al., 2010, Khunti et al., 2008; Joshi et al., 2010; Lloyd et al., 2008) found that every diabetes intervention must have a clear focus of the studied population and this evidence led to the formulation of CCAT criterion 1. In diabetes interventions (Mehler et al., 2004; Joshi et al., 2010) where communication was directly with primary providers, statistically significant improvements in diabetes related outcomes were reported. The service delivery providers in these two interventions were also highly trained in diabetes management and belonged to the same EMGs as the participants, which ensured linguistically-and-culturally concordance. Greenhalgh et al. (2005) and Lloyd et al. (2008) demonstrated that the use of alternative methods of communication with EMGs facilitated communication between the person with diabetes and their service providers. These studies led to the development of CCAT criteria 5, 6 and 7. After the fifth meeting, PZ drafted the first nine criteria which were circulated amongst the research team for peer review. At the sixth meeting, the research team agreed by a consensus. The final discussion led to formulating CCAT criterion 10.

The CCAT was piloted by three members of the research team on three random included interventions by cross-checking independent rating for consistency, and then used to assess study inclusion. A standard was set stating that cultural competence is achieved when a score of $\geq 70\%$ is attained. Although each criterion within the tool has been 'weighted' equally, it could be further developed as a self-assessment tool where the weighting of each criterion can be explored.

Box 3.1: The Papadopoulos, Tilki and Taylor Model for Developing Cultural Competence (1998)

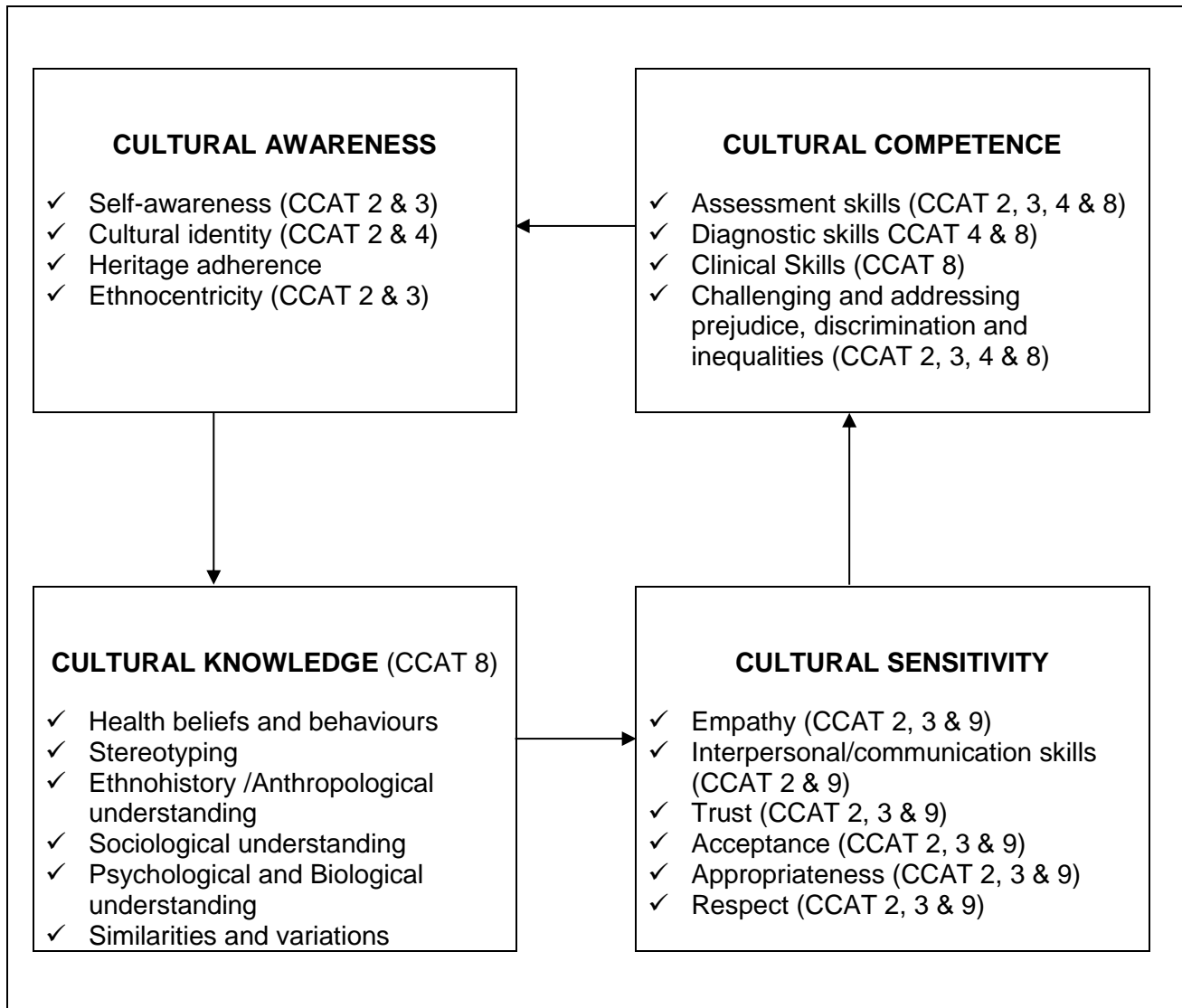


Table 3.2: Culturally-Competent Assessment Tool (CCAT) for Healthcare Interventions in EMGs

The questions are designed taking into considerations the Papadopoulos, Tilki & Taylor (1998) Model for ‘Developing Transcultural Competence.’

The following 10 questions are designed to help guide your decision systematically on the level of culturally-competent care service intervention:

- The first two questions are screening questions, which can be answered quickly. If the answer to both is ‘yes’, then you should proceed to the remaining questions. If the answer to questions 1 and 2 is ‘no’, the intervention is not culturally-competent.
- There is some overlap between some questions which is deliberate.
- Please tick the appropriate answer to each question. A number of italicised prompts are provided after each question. These are designed to remind you why the question is important. Note that where a ‘yes’ answer is provided, the entire score should be awarded.
- For an intervention to be culturally-competent, the answer must be ‘yes’ to numbers 1 and 2 and at least 5 or 6 other questions in 3 – 10 below.

Assessment Factors for Culturally-Competent Care Interventions

1. Does the intervention have a clear focus on ethnic minority groups?
 Yes [] No [] Unclear [] **10% []**

HINT: Consider most of the following

- ✓ *The studied population must be the minority of the majority population of the host country*
- ✓ *The primary aim/objectives of the intervention must be clearly defined to the culturally-competent element or elements*
- ✓ *An element of specific ethnic minority groups culture must be described*
- ✓ *Delivery staff group or health workers should be made clear*

2. Is the intervention sensitive to specific linguistic needs of the participants?
 Yes [] No [] Unclear [] **10% []**

HINT: Consider all or any of the following:

- ✓ *Is the intervention delivered in participants’ first or second language by healthcare workers or expert patients?*
- ✓ *Is the intervention delivered via an interpreter or translator?*
- ✓ *Is the intervention delivered with the aid of translated audio-visual aids for participants who speak or understand little of the service providers’ first language?*

Detailed Questions

3. Do the service providers demonstrate cultural awareness?
 Yes [] No [] Unclear [] **10% []**

HINT: Consider the following:

- ✓ *Do they demonstrate self-awareness of their own personal and professional cultural biases so as to understand how they influence their interactions with*

patients and other clients?

- ✓ Are they sufficiently aware of their own cultural values, cultural identities, and traditional health and belief practices to assess the influence of culture on a patient's or client's health beliefs and interpret the patient's explanatory model of their illness based on their cultural backgrounds (Shiu-Thornton, 2003)?
- ✓ Are they sufficiently aware of cultural diversity to deal with ethnocentricity?

4. Do the service providers have cultural knowledge?

Yes [] No [] Unclear []

10% []

HINT: Consider the following

- ✓ Do they have knowledge of cultures other than their own to understand the diversified needs of patients or clients?
- ✓ Do they value cultural diversity and the need to treat patients or clients as individuals?
- ✓ Do they demonstrate an acknowledgement of stereotypes, health inequalities, health beliefs and behaviours?
- ✓ Do they have clinical, cultural and humanistic knowledge to understand and collect relevant data on patients or clients, and undertake individual culturally-based physical assessments of patients or clients?

5. Do the service providers have specialist knowledge in the clinical condition?

Yes [] No [] Unclear []

10% []

HINT: Consider the following

- ✓ Do they have a sound scientific knowledge in the clinical condition under investigation?
- ✓ Have they undertaken relevant training to be competent in the delivering of the intervention?
- ✓ Can they use clinical and evidence-based knowledge to develop, assess, deliver, implement and evaluate individualised patient and client care?

6. Are the linguistic needs of patients or clients met by:

- | | | |
|---|----------------------------|----------------|
| (a) Health workers speaking the patient's/client's main language? | Yes [] No [] Unclear [] | 10% [] |
| (b) Health workers speaking the patient's/client's second language? | Yes [] No [] Unclear [] | 7% [] |
| (c) Interpreters (verbally/oral)? | Yes [] No [] Unclear [] | 5% [] |
| (d) Translators (written material)? | Yes [] No [] Unclear [] | 5% [] |
| (e) Audio-visual recorded aids? | Yes [] No [] Unclear [] | 3% [] |

HINT: Consider the appropriateness of media used to communicate with the patients or clients. Please choose only one answer, the most appropriate.

7. Are the health literacy needs of patients and/or clients met by the delivery health workers or expert patients (patients with full knowledge of the clinical condition)?

Yes [] No [] Unclear []

10% []

HINT: Consider the following	
<ul style="list-style-type: none"> ✓ Are they communicating at the appropriate level of the patients or clients? ✓ Is the scientific and/or health information understood by the patients or clients? ✓ Is the comprehension of the topic by patients/clients being assessed? 	
<hr/>	
8. Are the service providers culturally-competent in delivering the intervention?	
Yes [] No [] Unclear []	10% []
HINT: Consider the following:	
<ul style="list-style-type: none"> ✓ Do they have self-cultural awareness (please see #3 above)? ✓ Are they using clinical, assessment, and/or diagnostic skills appropriately? ✓ Are they taking into consideration the patient's/client's cultural beliefs, behaviours and care needs and addressing them where appropriate? ✓ Are they addressing cultural differences of patients/clients? 	
<hr/>	
9. Are the service providers culturally sensitive?	
Yes [] No [] Unclear []	10% []
HINT: Consider the following:	
<ul style="list-style-type: none"> ✓ Do they deliver care services and treatment in a non-judgmental manner? ✓ Do they show empathy in delivering care services to patients or clients? ✓ Do they consider patients or clients as true partners in their own care and involve them in decision-making? ✓ Do they have appropriate interpersonal relationships with patients and clients? ✓ Do they use effective communication skills to facilitate and negotiate the care needs of patients or clients? 	
<hr/>	
10. Does the intervention work?	
Yes [] No [] Unclear []	10% []
HINT: Consider at least two of the following:	
<ul style="list-style-type: none"> ✓ Does the intervention improve the quality of life (from primary and/or extrapolated evidence from secondary sources)? ✓ Is the intervention cost effective when compared to standard care procedures? ✓ Is there evidence of objective and subjective intervention outcomes reported by users and service providers (e.g. satisfaction with care, improvements in laboratory parameters, and improvement in knowledge of the clinical condition)? 	
Total:	100%

3.2.5. Data extraction and quality assessment of studies

Data extraction was piloted by PZ and amended in consultation with the research team. Data extraction included authors, year and country of publication, study aims, setting, intervention aims, number and ethnicity of participants, study methods, intervention components and delivery methods, comparison groups and outcome measures, notes and follow-up questions for the authors. Missing data were clarified with three authors. Included studies were quality assessed using Moher *et al.* (2010) for experimental studies, Popay *et al.* (1998) for the action research and qualitative studies and the Critical Appraisal Skills Programme (2006) for retrospective studies. Individual quality assessment tools enabled us to focus on the specific study designs appropriately.

3.3. Results

3.3.1. Available evidence and data analysis

The searches identified 320 papers (Figure 3.1). Fifty-seven potentially relevant abstracts were identified and full papers obtained, which were all in English. Eleven studies were included. The inter-coder reliability of the screening process was high (Kappa score 0.93). Forty were excluded because they were not culturally-competent interventions delivered to EMGs with diabetes. Following a third opinion, six additional studies were excluded because they were not explicitly related to EMGs with diabetes or culturally-competent or research. There was considerable heterogeneity among the included studies, hence a narrative synthesis of the evidence was undertaken.

3.3.2. Characteristics of studies

Of the eleven included studies (Table 3.3), there were five randomised-controlled trials (RCTs) (O'Hare *et al.*, 2004; Baradaran *et al.*, 2006; Bellary *et al.*, 2008; Joshi *et al.*, 2010;

Greenhalgh *et al.*, 2011); two qualitative action research studies (Povlsen *et al.*, 2005; Greenhalgh *et al.*, 2005) and two retrospective cohort studies (Hoppichler & Lechleitner, 2001; Mehler *et al.*, 2004); one quasi-experimental design study (Utz *et al.*, 2008); and one qualitative study involving focus groups/interviews (Wilson *et al.*, 1993). Studies were conducted in the UK (n=6), USA (n=3), Denmark (n=1) and Austria (n=1). Two thousand six and sixteen participants were recruited; African-Americans (n=182), African-Caribbean (n=22), Asians (n=165), Bangladeshis (n=42), non-specified ethnic minority participants (n=37), Hispanics (n=174), Russians (n=55), Turkish (n=39), with South Asians (n=2000) being the majority group studied from four UK-based RCTs. Nine studies included adults with type 2 diabetes (n=2540), one involved children with Type 1 diabetes (n=37) (Povlsen *et al.*, 2005), and another studied women with gestational diabetes (n=39) (Hoppichler & Lechleitner, 2001).

Table 3.3: Studies included in the review

Study references (first author & year)	Country / setting	Population	IN	CN	Com	Design	Mode & duration of intervention	Mode & duration of control	Delivery staff	Follow – up	Impact of intervention on outcomes
Greenhalgh <i>et al.</i> (2011)	UK Primary & secondary	South Asians & African – Caribbean	79	78	-	RCT with in-depth process evaluation	Unstructured group sessions in groups of 10-12 participants with sessions lasting for 2 hours held every fortnightly over 6 months	Usual care + structured standard diabetes education sessions in un-segregated by ethnicity groups led by a nurse & supported by an interpreter, if necessary	Trained bilingual health advocates (BHAs) in story-sharing models using an accredited curriculum over 12 weeks	12 months	HbA1C, p=0.364 Total Cholesterol ratio / HDL, P=0.783 SBP, P=0.123 Total wellbeing, p=0.512 Patient Enablement Instrument (secondary outcome), p=0.002 Overall, no significant differences between intervention and control groups in biomedical outcomes, although attendance was 79% in intervention and 35% in control arms (p<0.0001)
Joshi <i>et al.</i> (2010)	USA Community & OPD clinics	Hispanics & African American	234 (110 African Americans (AA) & 124 Hispanics)	100 (50 each)	-	RCT	4 group classes or one-to-one culture-specific education sessions with diabetes educators from the same ethnic backgrounds as participants including 2 weekly telephone follow-ups	Standard care (visit with a physician every 3 - 6 months)	2 trained nurse educators & 2 diabetic patients (1 from each group) who had completed a standardised chronic disease management training programme	2 years	HbA1C} AA - p<0.001 Hispanics - p=0.004 Lipids} AA - P=0.064 Hispanics-P=0.003 Microalbuminuria} AA - p=0.85 Hispanics - p=0.85 ED visits} AA-p<0.001 Hispanics - p=0.001 Hospitalisation} AA - p=0.010 Hispanics - p=0.845 BP} AA - I Hispanics – ND Eye checks} AA - I Hispanics - NR Weight} AA - I Hispanics - I

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Bellary <i>et al.</i> (2008)	UK Primary care	South Asians	868	618	-	RCT	Culturally sensitive enhanced individual care package with 4 hours per week of additional nurses' resources & prescribing algorithm	Standard routine care (using the same treatment protocols as intervention group)	Led by PN with support from 5 trained multilingual Asian link workers & DSN	2 years	MAP – p=0.018 Systolic BP – p=0.76 Diastolic BP – p=0.0001 Total cholesterol – p=0.37 HbA1C – p=0.11 CHD risk – p=0.97 Waist circumference – p=0.67 BMI - p<0.0001 Little financial impact – ICR of £28,933 per QALY gained / £30,000 per QALY
Baradaran <i>et al.</i> (2006)	UK Community & primary care	South Asians (Indians & Pakistanis)	59	59	27 white s	RCT	Group diabetes education of between 6 and 12 participants, having 3 sessions with each lasting 1-1.5 hours & completed within 3 months	Standard routine care	2 bilingual health educators (dietician & podiatrist)	6 months	Knowledge - p=0.27 Attitudes towards seriousness - p=0.76 Attitude towards complications – p=0.38 Practice - p=0.23
O'Hare <i>et al.</i> (2004)	UK Primary care	South Asians	180	181	-	RCT	Enhanced Individualised cultural sensitive care with additional nurses' resources per week & treatment algorithm	Standard routine care (using same treatment protocols as intervention group)	Led by PN with support from 2 multilingual Asian link workers & Community DSN	1 year	Systolic BP – p=0.035 Diastolic BP – p=0.003 Total cholesterol – p=0.005 HbA1C – p=0.866 Financial investment produced little improvement £365 / £264
Povlsen <i>et al.</i> (2005)	Denmark Community	7 EMGs – 65% Muslims	37 families	N/A	-	Action research	Development of an adapted & translated educational material and guidelines for HCPs; subsequent re-education of children with T1DM and their families	N/A	Led by experienced nurse in diabetes care, immigration & Muslim customs and supported by interpreters	6 months	Educational material received with enthusiasm. HbA1C – p=0.01 but increased after follow-up. Educational material & strategies – I Group attitude varied with some liking group

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								in 7 groups of 4 - 6 or 1-1 based on age & ethnicity of the children. Sessions given in their parent's native language or Danish		and clinical dieticians		participation & others not. Knowledge of diabetes management – I That is, diabetes education improved diabetes knowledge level and led to short term health benefits
Greenhalgh <i>et al.</i> (2005)	UK Community	Bangladeshi s	42	N/A			Action research using narrative methods	Diabetes support & education groups led by BHAs using 'story-telling' format in partnership with clinicians, managers and service users. 10 formal programmes consisting of 3 hours sessions undertaken over 12 weeks	N/A	Bilingual health advocates (BHAs) & researchers	18 months	Development of an intervention for diabetes education aimed to engage trained BHAs to facilitate narratives or story-telling approaches as part of a programme to improve diabetes management for neglected Bangladeshi population. A user group led by BHAs successfully implemented though not in all cases. Glucose concentrations of 'active participants' improved
Mehler <i>et al.</i> (2004)	USA Community & OPD	Russians	55 (32 females & 23 males)	N/A	-		Retrospective cohort	Individualised care to assess outcomes pre / post arrival of a bilingual Russian internist. Cohort had between 1 and 6 internal medication clinic visits annually	N/A	Trained bilingual Russian internist in language & culture concordance	1-6 clinics reviews per year	HbA1C – p=0.007 Lipid (LDL) – p=0.0002 Systolic Bp – p=0.3 Diastolic BP – p=0.0002
Hoppichler <i>et al.</i> (2001)	Austria OPD	Mediterranean Turkish (MT) & Caucasian Austrian	39 MT	N/A	72 CA		Retrospective cohort	Individualised weekly gestational diabetes counselling including dietary	N/A	Led by a Dietician & Nurse educator and supported by	Not clear	31% Turkish women (not picked up at initial visit) found to be illiterates during intervention and a

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		(CA) women with gestational diabetes							advice on food intake, insulin administration and techniques, signs and symptoms of hypoglycaemia and control procedures. Therapeutic regimen including dietary recommendations and insulin therapy instructions adapted to Turkish eating habits.		trained translators		personalised education approach adopted with them. No significant differences in the clinical outcomes (family history of DM, HbA1C, weight& etc.) except with eating habits as MT reported high intake of fat and carbohydrates, preferred female HCPs and adherent to religious beliefs. Cultural appropriate care leading to similar clinical outcomes
Utz <i>et al.</i> (2008)	USA Community	African Americans	22 (18 female & 4 male)	N/A	-	Quasi-experimental		Culturally tailored Group versus Individual DSME intervention to compare the impact and effectiveness on outcomes of self-management & HbA1C control of participants with T2DM of 2 hours weekly over 8 weeks. Each participant paid \$75 and other small gifts periodically	N/A	Led by 2 certified diabetes educators from the same ethnic backgrounds	10 weeks	HbA1C, self-care actions, Self-efficacy level, goal attainment, and satisfaction with DSME. HbA1C, self-care activities and goal attainment improved slightly in both groups over follow-up. Statistical trends indicated improved scores on dietary actions, foot care, goal attainment, and empowerment in the Group DSME, but differences not statistically significant	
Wilson <i>et al.</i> (1993)	UK OPD	Asians	165 (96 male & 69 female)	N/A	-	Qualitative group discussion interview	/	Implementing a diabetes group education programme (one off 2.5 hours session in groups of 10 – 12 over 2 years) that promotes improvements in	N/A	Led by Asian link worker trained in diabetes & supported by Diabetes Specialist Health Visitor	1 off session	Diabetes education programme for Asians was successful as it was tailored to their linguistic and cultural needs and improved their diabetes care. Two initial recruitments were poor and improved by Asian link worker	

understanding and
self-management
for Asians with
diabetes

making individual home
visits. Public awareness
of diabetes in the
community improved by
providing health
education in social
venues such as temple.

Legend

AAs (African-Americans), BMI (body mass index), CHD (coronary heart disease), CN (number of participants in the control arm), Com (comparison), DSME (diabetes self-management education), ED (emergency department), HbA1C (glycated haemoglobin), HDL (high-density lipoprotein), I (improvement), ICR (Incremental cost-effectiveness ratio), IN (number of participants in the intervention arm), LDL (low-density lipoprotein), MAP (main atrial pressure), ND (no difference), NR (not reported), PN (practice nurse)

3.3.3. Risk of bias

Three of the experimental studies were of 'A' quality (Greenhalgh *et al.*, 2011; Bellary *et al.*, 2008; O'Hare *et al.*, 2004) with the remainder (Joshi *et al.*, 2010; Baradaran *et al.*, 2006; Utz *et al.*, 2008) of 'B' quality using Moher *et al.*'s criteria (Table 3.4) (Moher *et al.*, 2010). All the trials clearly described withdrawal and dropout rates, including follow-up methodologies, and presented the interventions' outcome results. Three trials (O'Hare *et al.*, 2004; Bellary *et al.*, 2008; Greenhalgh *et al.*, 2011) included power calculations and these were greater than 80%. These studies also reported results by intention to treat. The flow of participants was not represented in a consort style diagram in two studies (Joshi *et al.*, 2010; Utz *et al.*, 2008). There were no allocation concealments of participants and intention to treat analyses were unclear in two RCTs (Baradaran *et al.*, 2006; Joshi *et al.*, 2010). All six studies were conducted in only two countries, UK (n=4) and USA (n=2). Overall quality assessment of the eleven studies found 5 of the studies to be good quality (scored A) (Mehler *et al.*, 2004; Povlsen *et al.*, 2005; Greenhalgh *et al.*, 2011; Bellary *et al.*, 2008; O'Hare *et al.*, 2004) by meeting >79% of the quality criteria and 6 of moderate quality (B), meeting 50%-79 of the quality criteria (Tables 3.5 to 3.6).

Table 3.4: Risk of bias assessments in experimental studies [RCTs + quasi experimental studies [From Moher *et al.* (2010)]]

		Quality assessment criteria												
Study References		1	2 (a+b)	3	4	5	6	7	8	9	10	11	12 (a+b+c)	%
Greenhalgh et al. (2011)		Yes	Yes/No	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes / Yes / Yes	87% (A)
Joshi et al. (2010)		Yes	No / No	Yes	No	No	No	Yes	No	Yes	Can't tell	Yes	Yes / Yes / Yes	53% (B)
Bellary et al. (2008)		Yes	No / Can't tell	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes / Yes / Yes	80% (A)
Baradaran et al. (2006)		Yes	No / Can't tell	Yes	No	Yes	No	Yes	No	Yes	Can't tell	Yes	Yes / Yes / Yes	60% (B)
O'Hare et al. (2004)		Yes	No / Can't tell	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes / Yes / Yes	80% (A)
Utz et al. (2008)		Yes	No / No	Yes	No	No	No	Yes	No	Yes	No	Yes	Yes / Yes / Yes	53% (B)

Questions relating to the quality criteria for assessment of the above experimental studies [Adapted from Moher et al. (2010)]	
1	Is the study described as randomised and was the method appropriate?
2	a) Were participants adequately blinded? b) Was outcome assessment adequately blind?
3	Is there a description of withdrawals and dropouts and is this adequate?
4	Is allocation concealment described and was the method appropriate?
5	Is the flow of participants through each stage represented in a consort style diagram?
6	Did at least 80% of the number randomised provide data at the follow up of interest?
7	Are clearly defined primary/secondary outcomes given?
8	Is there a calculation to determine the sample size described and was the method appropriate?
9	Is there a comparison of groups at baseline on demographic/clinical characteristics that may influence the effectiveness of the intervention, including outcome measures?
10	Is an explicit ITT analysis described?
11	Is an adequate summary of results for each outcome provided, including for non-significant results?
12	a) Is the sample explicitly defined? b) Is the method of recruitment adequately described? c) Are precise details of the intervention/conditions for each group provided?

NOTE: Each of the 15 criteria above answers 'yes' or 'no' or 'can't tell' and score at least 8/15 (53%) in order for the study to be included

Scoring classification of the quality of included experimental studies

- Good quality studies must answer 'yes' to 80%-100% of the quality assessment criteria and scored as 'A'
- Moderate quality studies must answer 'yes' to 50%-79% of the quality assessment criteria and scored as 'B'
- Weak quality studies must answer 'yes' to less than 50% of the quality assessment criteria and scored as 'C'

Table 3.5: Quality assessment for included qualitative and action research studies (Popay *et al.*, 1998)

Study References	Quality assessment criteria						%
	1	2	3	4	5	6	
Greenhalgh <i>et al.</i> (2005)- AR	Yes	Can't tell	Yes	Yes	Yes	Can't tell	67% (B)
Povlsen <i>et al.</i> (2005) – AR	Yes	Yes	Yes	Yes	Yes	No	83% (A)
Wilson <i>et al.</i> (1993) – QR	Yes	Yes	No	Yes	Yes	No	67% (B)

Questions relating to the quality criteria for assessment of qualitative research	
1	A primary marker: Is the research aiming to explore the subjective meanings that people give to particular experiences of interventions?
2	Context sensitive: Has the research been designed in such a way as to enable it to be sensitive / flexible to changes occurring during the study?
3	Sampling strategy: Has the study sample been selected in a purposeful way shaped by theory and/or attention to the diverse contexts and meanings that the study is aiming to explore?
4	Data quality: Are different sources of knowledge / understanding about issues being explored compared?
5	Theoretical adequacy: Do the researchers make explicit the process by which they move from data to interpretation?
6	Generalisability: If claims are made to generalisability, do these follow logically and / or theoretically from the data?

NOTE: Each of the six criteria above answers 'yes' or 'no' or 'can't tell' and score at least 3/6 (50%) in order for the study to be included

Scoring classification of the quality of the included studies

- Good quality studies must answer 'yes' to 80%-100% of the quality assessment criteria and scored as 'A'
- Moderate quality studies must answer 'yes' to 50%-79% of the quality assessment criteria and scored as 'B'
- Weak quality studies must answer 'yes' to less than 50% of the quality assessment criteria and scored as 'C'

Coders from the table: AR for action research and QR for qualitative research.

Table 3.6: Quality assessment for included retrospective cohort studies (Critical Appraisal Skills Programme, 2006)

		Quality assessment criteria													
Study References		1	2	3	4	5	6	7	8	9	10	11	12	%	
Mehler	<i>et al.</i> (2004)	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Yes	Yes	83% (A)	
Hoppichler	<i>et al.</i> (2001)	Yes	Yes	Yes	No	Yes	Can't tell	Can't tell	Yes	Yes	No	Can't tell	Can't tell	50% (B)	

Questions relating to the quality criteria for assessment of the above cohort studies	
1	Did the study address a clearly focused issue?
2	Did the authors use an appropriate method to answer their question?
3	Was the cohort recruited in an acceptable way?
4	Was the exposure accurately measured to minimise bias?
5	Was the outcome accurately measured to minimise bias?
6	Have the authors identified all important confounding factors and/or have they taken account of the confounding factors in the design and/or analysis?
7	Was the follow up of subjects complete enough and/or was the follow up of subjects long enough?
8	What are the results of this study?
9	How precise are the results and/or how precise is the estimate of the risk?
10	Do you believe the results?
11	Can the results be applied to the local population?
12	Do the results of this study fit with other available evidence?

NOTE: Each of the twelve criteria above answers 'yes' or 'no' or 'can't tell' and score at least 6/12 (50%) in order for the study to be included.

Scoring classification of the quality of the included studies

Good quality studies must answer 'yes' to 80%-100% of the quality assessment criteria and scored as 'A'

Moderate quality studies must answer 'yes' to 50%-79% of the quality assessment criteria and scored as 'B'

Weak quality studies must answer 'yes' to less than 50% of the quality assessment criteria and scored as 'C'.

3.3.4. Cultural competence of interventions

The CCAT was used to assess the interventions, and found 64% (n=7) of the interventions to be highly culturally-competent (scoring 90%-100%). The remaining 36% (n=4) were moderately culturally-competent by scoring 70%-89% (Table 3.7). Five studies described their interventions as fully culturally-competent (Joshi *et al.*, 2010; Mehler *et al.*, 2004; Utz *et al.*, 2008; Wilson *et al.*, 1993; Baradaran *et al.*, 2006), which were confirmed when assessed systematically using the CCAT.

Table 3.7: Culturally-competent assessment of included studies based on a novel devised tool titled: Culturally-Competent Assessment Tool (CCAT) for Healthcare Interventions in ethnic minority groups by these research authors

Culturally Competent Factors											
Study References	1	2	3	4	5	6	7	8	9	10	%
Greenhalgh <i>et al.</i> (2011)	Yes	Yes	Yes	Yes	No	Yes (a)	Yes	Yes	Yes	Yes	90% (A)
Joshi <i>et al.</i> (2010)	Yes	Yes	Yes	Yes	Yes	Yes (a)	Yes	Yes	Yes	Yes	100% (A)
Bellary <i>et al.</i> (2008)	Yes	Yes	Yes	Yes	Yes	Yes (c)	Unclear	Yes	Yes	Yes	85% (B)
Baradaran <i>et al.</i> (2006)	Yes	Yes	Yes	Yes	Yes	Yes (a)	Yes	Yes	Yes	Yes	100% (A)
O'Hare <i>et al.</i> (2004)	Yes	Yes	Yes	Yes	Yes	Yes (c)	Unclear	Yes	Yes	Yes	85% (B)
Utz <i>et al.</i> (2008)	Yes	Yes	Yes	Yes	Yes	Yes (a)	Yes	Yes	Yes	Yes	100% (A)
Greenhalgh <i>et al.</i> (2005)	Yes	Yes	Yes	Yes	Yes	Yes (a)	Unclear	Yes	Yes	Yes	90% (A)
Povlsen <i>et al.</i> (2005)	Yes	Yes	Yes	Yes	Yes	Yes (c)	Unclear	Yes	Yes	Yes	85% (B)
Mehler <i>et al.</i> (2004)	Yes	Yes	Yes	Yes	Yes	Yes (a)	Yes	Yes	Yes	Yes	100% (A)
Hoppichler <i>et al.</i> (2001)	Yes	Yes	Yes	Yes	Yes	Yes (d)	Unclear	Yes	Yes	Yes	85% (B)
Wilson <i>et al.</i> (1993)	Yes	Yes	Yes	Yes	Yes	Yes (a)	Yes	Yes	Yes	Yes	100% (A)

Culturally-Competent Assessment Tool for Healthcare Interventions in ethnic minority groups by this research authors

Assessment Factors for Culturally-Competent Care Interventions

- 1 Does the intervention have a clear focus on ethnic minority groups?
- 2 Is the intervention sensitive to the specific linguistic needs of the participants?
- 3 Do the service providers demonstrate cultural awareness?
- 4 Do the service providers have cultural knowledge?
- 5 Do the service providers have specialist knowledge in the clinical condition?
- 6 Are the linguistic needs of patients/clients met by (a) health workers speaking the patient's/client's main language? (b) health workers speaking the patient's/client's second language? (c) interpreters? (d) translators? (e) Audio-visual recorded aids?
- 7 Are the health literacy needs of patients and/or clients met by the delivery health workers or expert patients?
- 8 Are the service providers culturally-competent in delivering the intervention?
- 9 Are the service providers culturally sensitive?
- 10 Does the intervention work?

NOTE: For an intervention to be culturally-competent, the answer is 'yes' to # 1 & 2 and at least 6 other questions in 3-10 scoring above (70%)

Scoring classification of the quality of the culturally-competent intervention

- Highly culturally-competent must answer 'yes' to 90%-100% of the assessment factors or criteria and scored as 'A'
- Moderately culturally-competent intervention must answer 'yes' to at least 70%-89% (B)
- Low culturally-competent intervention scores less than 70% (C).

3.3.5. Development and types of interventions

All eleven studies were complex interventions composed of components acting independently and/or interdependently (Campbell *et al.*, 2007). Four interventions were one-to-one, (O'Hare *et al.*, 2004; Bellary *et al.*, 2008; Mehler *et al.*, 2004; Hoppichler & Lechleitner, 2001), four used group sessions only (Wilson *et al.*, 1993; Baradaran *et al.*, 2006; Greenhalgh *et al.*, 2005; Greenhalgh *et al.*, 2011), and the other three applied both approaches (Joshi *et al.*, 2010; Povlsen *et al.*, 2005; Utz *et al.*, 2008).

3.3.6. Components and delivering of interventions

In two studies involving Bangladeshi subjects, pictorial material and videos were used for teaching/learning (Greenhalgh *et al.*, 2005; Greenhalgh *et al.*, 2011). Two USA studies with African-Americans successfully used financial incentives to recruit and retain participants (Utz *et al.*, 2008; Joshi *et al.*, 2010). Three of eleven studies (Greenhalgh *et al.*, 2011; Greenhalgh *et al.*, 2005; Wilson *et al.*, 1993) implemented informal learning methods amongst peers; however, in the one using unstructured learning, the primary outcome measures did not improve when compared with the control group (Greenhalgh *et al.*, 2011).

The number and duration of intervention sessions varied. In the group education sessions, one intervention offered a one-off session lasting 2.5 hours (Wilson *et al.*, 1993), one implemented 3 sessions of 1-1.5 hours per participant over 3 months (Baradaran *et al.*, 2006), and other two offered fortnightly 2 hours sessions over 6 months (Greenhalgh *et al.*, 2011) and 10 formal programmes consisting of 3 hours per participant over 12 weeks (Greenhalgh *et al.*, 2005), respectively. Of the four interventions that provided individualised sessions, one was extra nurse resources of 4 hours per week (Bellary *et al.*, 2008), two unspecified weekly support of extra nurse resources (O'Hare *et al.*, 2004), and

dietitian/nurse educator resources (Hoppichler & Lechleitner, 2001). The other study undertook between one and six internal medication clinic visits annually (Mehler *et al.*, 2004). The three studies (Joshi *et al.*, 2010; Povlsen *et al.*, 2005; Utz *et al.*, 2008), which used mixed delivery method approaches comprised: one-one sessions of three meetings lasting 10-15 minutes per participant along with the group sessions of 2 hours weekly per group over 8 weeks (Utz *et al.*, 2008); one provided 8 group meetings over 10 months and unspecified individualised sessions to four families, where an ethnic group could not be formed (Povlsen *et al.*, 2005). The other implemented either four intensive education sessions in groups or one-one, totalling 10-16 sessions per patients (Joshi *et al.*, 2010). Apart from two studies (Wilson *et al.*, 1993; Mehler *et al.*, 2004), all the interventions clearly reported a follow-up period; the shortest was ten weeks (Utz *et al.*, 2008), and the longest two years (Joshi *et al.*, 2010; Bellary *et al.*, 2008).

Nine interventions were delivered in primary and community care settings (Joshi *et al.*, 2010; Greenhalgh *et al.*, 2011; Bellary *et al.*, 2008; Baradaran *et al.*, 2006; O'Hare *et al.*, 2004; Povlsen *et al.*, 2005; Greenhalgh *et al.*, 2005; Mehler *et al.*, 2004; Utz *et al.*, 2008). Of these, three were also delivered in hospital care settings (OPD) (Greenhalgh *et al.*, 2011; Joshi *et al.*, 2010; Mehler *et al.*, 2004). Two studies (Hoppichler & Lechleitner, 2001; Wilson *et al.*, 1993) delivered their interventions exclusively in hospital settings. Three UK-based studies (Wilson *et al.*, 1993; O'Hare *et al.*, 2004; Bellary *et al.*, 2008) used multilingual Asian link workers (ALWs). Three interventions (Joshi *et al.*, 2010; Mehler *et al.*, 2004; Utz *et al.*, 2008) had their providers from the same ethnic backgrounds as the participants. Two used Bilingual Health Advocates to deliver their interventions (Greenhalgh *et al.*, 2005; Greenhalgh *et al.*, 2011). The other three studies utilised providers with varied competences: two experienced bilingual health educators (Baradaran *et al.*, 2006), an experienced nurse in diabetes and Muslim customs supported by

interpreters (Povlsen *et al.*, 2005), and a dietitian and nurse educator, supported by a translator (Hoppichler & Lechleitner, 2001). The settings, service providers and model of delivering were similar in the two nurse-led interventions (Bellary *et al.*, 2008; O'Hare *et al.*, 2004).

3.3.7. Training to deliver culturally-competent interventions

Six studies explicitly described the diabetes cultural competence-related training of the interventionists, of which four comprised of cultural competencies and/or standardised chronic disease management (Bellary *et al.*, 2008; Joshi *et al.*, 2010; Utz *et al.*, 2008; Wilson *et al.*, 1993); two of cultural-competence training programmes and story-sharing models using accredited curriculum over 12 weeks (Greenhalgh *et al.*, 2005; Greenhalgh *et al.*, 2011). All eleven studies mentioned the qualifications of the service providers, which varied from primary education to degree level. In five studies, providers were certified to a minimum of registered nurse/dietitian level (Utz *et al.*, 2008; Hoppichler & Lechleitner, 2001; Povlsen *et al.*, 2005; Baradaran *et al.*, 2006; Joshi *et al.*, 2010), and one was a medical doctor (Mehler *et al.*, 2004). One intervention (Povlsen *et al.*, 2005) was delivered by a nurse experienced in diabetes care, immigration and Muslim customs with support from interpreters and clinical dietitians. The diabetes-related training in the link worker's study (O'Hare *et al.*, 2004) was unclear. The link worker's roles were mainly limited to liaison and interpretations. The primary providers in three studies (Povlsen *et al.*, 2005; O'Hare *et al.*, 2004; Hoppichler & Lechleitner, 2001) appeared not to be linguistically-competent by using interpreters/translators. Overall, the USA studies provided greater details about the training of their interventionists. Nonetheless, eight studies reported successful use of locally available culturally-appropriate media/communication tools including the engagement of community or religious leaders to access participants and maintain motivation, including the use of delivery staff from the same ethnic backgrounds

as participants (Wilson *et al.*, 1993; Mehler *et al.*, 2004; O'Hare *et al.*, 2004; Greenhalgh *et al.*, 2005; Bellary *et al.*, 2008; Utz *et al.*, 2008; Joshi *et al.*, 2010).

3.3.8. Diabetes-related outcome measures

Across the eleven studies, twenty-two outcomes were reported, including; 12 clinical, five psychosocial, three lifestyle and two health care utilisation. Of these, five were objectively measured (e.g. HbA1c), eight were self-report (e.g. satisfaction with care) and nine measured by the research or clinical team (e.g. BMI). All but one study (Greenhalgh *et al.*, 2011) reported at least two positive impacts on their participants' diabetes-related outcomes.

3.3.9. Impact on clinical outcomes

HbA1C was the main clinical outcome of interest and was reported in nine of the eleven included studies: four of the RCTs evaluated Hb1AC changes (Greenhalgh *et al.*, 2011; Joshi *et al.*, 2010; Bellary *et al.*, 2008; O'Hare *et al.*, 2004), with only one (Joshi *et al.*, 2010) reporting statistically significant between group changes in both Hispanics (decreased from 80mmol/mol (9.5%) to 65mmol/mol (8.1%), $P=0.004$) and African-Americans (92mmol/mol (10.6%) to 66mmol/mol (8.2%), $P<0.001$). There were no improvements in HbA1C in the other three RCTs. Four RCTs (Greenhalgh *et al.*, 2011; Joshi *et al.*, 2010; Bellary *et al.*, 2008; O'Hare *et al.*, 2004) also evaluated total cholesterol levels and blood pressure (BP). Statistically significant total cholesterol reduction in the intervention groups compared with controls were reported in two RCTs: at immediately post-intervention, there was an 18% ($P=0.003$) reduction in the number of Hispanic participants with total cholesterol over 200 mg/dl (Joshi *et al.*, 2010), and at one year a reduction of 0.4mmol/l, $P=0.005$ in the studied South Asian population (O'Hare *et al.*, 2004). The reduction in diastolic BP was statistically significant in two RCTs (O'Hare *et al.*, 2004; Bellary *et al.*, 2008) with changes in the intervention groups compared with controls

lowered by 3.4 mmHg ($P=0.003$) at the end of the one year period in one RCT (O'Hare *et al.*, 2004), and after two years a reduction of 1.6 mmHg, $P=0.007$) in the other RCT (Bellary *et al.*, 2008). The only quasi-experimental study (Utz *et al.*, 2008) found small HbA1C improvement in both the Group and Individualised Diabetes Self-management. One of the two action research studies (Povlsen *et al.*, 2005) measured HbA1C changes, which decreased significantly immediately post-intervention (from 77mmol/mol (9.2%) to 70mmol/mol (8.6%), $P=0.01$), when compared with baseline parameters but was not sustained at the six month follow-up (increased to 76mmol/mol (9.1%). The second action research study commented that glucose concentration of 'active participants' did improve (Greenhalgh *et al.*, 2005). Only one of the two retrospective cohort studies (Mehler *et al.*, 2004) reported statistically significant changes in HbA1C (decreased from 68mmol/mol (8.4%) to 64mmol/mol (8.0%); $P=0.007$). No significant differences between the groups were reported by the other study (Hoppichler & Lechleitner, 2001).

3.3.10. Impact on knowledge, attitude change and self-efficacy

Only one of the RCTs (Baradaran *et al.*, 2006) assessed diabetes knowledge, attitude towards seriousness/complications and self-care practices. Immediately post-intervention, the mean improvement changes between the ethnic intervention and control groups respectively were reported as: knowledge (1.72 (5.4), 0.47 (4.5); $P=0.27$); attitude towards seriousness (1.21 (2.4), 1.38 (2.2); $P=0.76$); self-care practice (1.02 (2.2), 0.26 (3.2); $P=0.23$), showing no significant improvement between group differences. A qualitative study reported a small improvement in knowledge and attitude towards seriousness to diabetes care (Povlsen *et al.*, 2005). These authors, who report that the educational materials and topics were received with enthusiasm, though many of the topics were considered 'difficult' by participants, found that their intervention was successful in terms of participants citing what they had learned from the education programme and how it met

their needs. The quasi experimental study (Utz *et al.*, 2008) found an increase change scores on measures of self-efficacy over the 10-week study duration in the intervention groups for participants receiving the Group DSME (+3.58 (5.43)) over Individual DSME, which were reduced (-1.13 (7.12); $P=0.111$) although the reduction was not statistically significant. A further qualitative study reported improvement in patient knowledge and outcomes (Wilson *et al.*, 1993). In relation to health behaviour, one study (Povlsen *et al.*, 2005) reported significant differences between the families associated with culture. The general attitude of participants varied, with some not liking to work with peers in groups and had to be provided with individualised education sessions, which had time and resources implications.

3.3.11. Evaluation of cost effectiveness

Only one study formally assessed the cost-effectiveness of their intervention (Bellary *et al.*, 2008). It analysed programme cost of £434 per patient over 2 years, and calculated cost in terms of quality-adjusted life year (QALY), which equated to an incremental cost-effectiveness ratio of £28,933 per QALY gained compared well with National Institute for Health and Clinical Excellence (NICE) suggestive norm of £30,000 per QALY (Raftery, 2001). The little cost savings were offset by increased consultation length of 4 hours weekly of additional nurses' input. One of two studies estimated annual cost per patient at £365 compared with £264 for treating type 2 diabetes (O'Hare *et al.*, 2004), and the other estimated the cost of training bilingual healthcare advocates or volunteers as group facilitator at £1500 and £345 to deliver the 12-week story-sharing course per patient (Greenhalgh *et al.*, 2011).

3.4. Discussion

3.4.1. Statement of main findings

This was a systematic review which included RCTs, quasi-experimental, qualitative research primary study designs reporting on the impact of culturally-competent interventions on any outcome measures to any ethnic minority population within a majority population globally with any type of diabetes. The review found a small number of papers of heterogeneous research design. Ten of the eleven included studies reported at least two positive impacts on a wide range of patient level diabetes outcomes. The positive impact of most of the interventions (see Table 3.3) was limited. The success of this positive impact was found in the interventions which were structured, coupled with the fact that the service providers adapted teaching and learning methods which met cultural and community needs, fundamental to good care (Hawthorne *et al.*, 2010). Whilst short-term improvements were observed in some studies in clinical and psychosocial outcomes, these changes were short lived. There is some indication that knowledge improves as a result of culturally-competent intervention. All studies were of moderate or good quality in relation to the characteristics of their particular design. South Asian communities were the focus of diabetes-related culturally-competent intervention research in the UK and African-Americans in the USA studies. These groups are the sizeable minority populations in many countries worldwide, and are among the most susceptible to diabetes and related complications in both countries (Mokdad *et al.*, 2001; Khunti *et al.*, 2008).

3.4.2. Strengths and limitations

As with the systematic review on cultural barriers in Chapter Two, the search criteria of this review included all EMGs with all types of diabetes as well as culturally-competent interventions globally. Interventions of any research design, (from wide range of sources including experts), were assessed and included, which were culturally-competent, using

the CCAT, to ensure the inclusion of all relevant interventions previously undertaken in the area. This design was inclusive as previous systematic reviews limited their search to specific EMGs (Gill *et al.*, 2007; Whittemore, 2007; Alam *et al.*, 2008), study types (Saxena *et al.*, 2007; Hawthorne *et al.*, 2010) or type 2 diabetes (Whittemore, 2007; Khunti *et al.*, 2008; Hawthorne *et al.*, 2010), and did not formally assess the level of cultural competence in interventions. The included eleven studies were assessed for both methodological quality and cultural-competence. The review is limited by the different methodological studies. The lack of age restriction of participants posed a challenge in drawing any conclusive views due to the heterogeneity of the populations. Again, as only published studies were included, some relevant ongoing studies may have been excluded. The definitions of 'ethnic minority groups' and 'cultural competence' have been signposted in this review. However, these terms have been recognised as having no unique meanings (Bulmer, 1996; Mizrahi *et al.*, 2001).

The CCAT performed well as a tool to assess the cultural competence of the included studies. It was developed alongside the review and its content was informed by the contextual data surrounding the interventions under scrutiny. In this way the review informed the CCAT and may well account for its success in determining that the included studies were delivering interventions with a strong basis of cultural competence. The CCAT is not diabetes-specific and theoretically could be used to assess the cultural competence of interventions aimed at any ethnic minority health care population. It could also be used to inform the development of a new culturally-competent intervention and the next steps in its development is to undertake some of this work to further test its validity and reliability. However, further empirical refinement of concepts within the CCAT is required.

3.4.3. Findings in relation to other studies

No specific trends were identified in terms of interventions that can produce notable improvements in HbA1C in the South Asian populations. A previous review involving this population had suggested that trials of longer durations may have a significant improvement in glycaemic control in this group (Khunti *et al.*, 2008). However, the two similar nurse-led interventions, which studied South Asians with one year follow-up (O'Hare *et al.*, 2004) and two years follow-up (Bellary *et al.*, 2008), using 361 and 1486 participants respectively to evaluate HbA1C changes produced similar outcomes. This may be explained by the use of the link worker model which meant that communication between the patients and the primary providers was sometimes indirect. The two USA studies (Mehler *et al.*, 2004; Joshi *et al.*, 2010) where communication was direct with primary providers, produced statistically significant improvements in HbA1C and lipids, albeit of limited duration as well as in ED visits (Joshi *et al.*, 2010) and diastolic BP (Mehler *et al.*, 2004). These two studies (Mehler *et al.*, 2004; Joshi *et al.*, 2010) that reported the most statistically significant diabetes-related improvements used dual interventions settings (community and hospital). Their delivery providers were highly trained in diabetes management and belonged to the same EMGs as the participants, therefore, they were linguistically-and-culturally-competent. However, it would appear that the reported outcomes might have come from delivering the interventions over a longer period because, following the same procedure for a shorter period (Utz *et al.*, 2008) only produced small benefits. This has been confirmed in other diabetes-related reviews, which recommended that results reported immediately following an intervention or those after a brief follow-up period have limited reliability for informing commissioning decisions (Loveman *et al.*, 2008; Hawthorne *et al.*, 2010). Furthermore, this researcher would argue that what is specifically lacking in diabetes care to EMGs accounting for poorer care and outcomes could be attributed to culturally-competent resource constricts to ensure

meaningful interactions between minority patients and their service providers, in addition to a lack of organisational accountability to tailor individualised diabetes care services to EMGs.

3.4.3.1. Communication

Communication in relation to intervention delivery and the assessment of outcome may both impact on the findings of these studies. The results of this review showed that communications between service providers and participants in some interventions were indirect, necessitating the use of link workers or interpreters/translators. The evidence suggests that communication barriers may inhibit the uptake of the intervention and the use of psycho-social and knowledge assessment tools which are essential in determining the effectiveness of diabetes-related interventions (Alam *et al.*, 2008; Greenhalgh, 2008). They argue that communication must not only be seen in terms of linguistic barriers because our health-seeking behaviour is influenced by our cultural backgrounds, belief systems and identity as well as our past experiences in our countries of origin. Translators/interpreters may not, in all cases, be able to understand the communications of some of the patients or their providers and the meaning of what would have been said will be misleading. As some participants were found to be illiterate in one study (Hoppichler & Lechleitner, 2001), the proposed remedy to this, is the use of tools such as audio-video methods of delivery with SAs (Lloyd *et al.*, 2008; Roy & Lloyd, 2008).

3.5. Conclusion and recommendations for future research

The findings suggest a need for a robust research agenda on culturally-competent interventions in diabetes care services. The presence of cultural-competency components in every healthcare service intervention should be assessed to ensure it meets the needs of specific ethnic minority populations. The CCAT can be further evaluated and

strengthened to inform this agenda. As not all the intervention providers had formal training in diabetes and cultural competence, it is difficult to assess the resource needed to ensure successful interventions. Therefore, further studies are needed to investigate if formal culturally-competent training for diabetes service providers generally produces a positive effect in diabetes-related outcomes in ethnic minority populations. Limited evidence on cost-effectiveness is available and we recommend that culturally-competent interventions should include cost-effectiveness evaluation in their designs at the outset. Such findings may then be used to inform future commissioning of diabetes services and buy-in by its commissioners (Hawthorne *et al.*, 2010). Furthermore, culturally-competent diabetes service interventions involving EMGs should be designed to evaluate the satisfaction levels of patients and service providers which may improve patient concordance and providers' job satisfaction (Zeh, 2010). Healthcare organisations should have culturally-competent staff and services, which should result in positive health outcomes to EMGs (Ornelas, 2008). Whilst there are some benefits for EMGs to conserve their cultural identities within their host nations, service providers should learn and be aware of the EMGs' cultural and linguistic needs to ensure that their perceived healthcare needs are met in a sensitive manner. EMGs should be encouraged and assisted by service providers towards community integration of their host nations. Although challenging, the pursuit for culturally-competent healthcare systems in every nation requires further investigation to meet the increasing needs of EMGs (Bhopal, 2012).

CHAPTER FOUR

METHODOLOGY FOR THE RESEARCH

4.1. Introduction

Some research questions involving ethnic minority groups (EMGs) with diabetes have been addressed using either qualitative (e.g. Stone *et al.*, 2005; Brown *et al.*, 2006; Lawton *et al.*, 2006) or quantitative methodologies (e.g. Sedgwick *et al.*, 2003; Povlsen *et al.*, 2005a), whilst others have combined both methodologies, called mixed methods [MM] (e.g. Greenhalgh *et al.*, 2006; Lloyd *et al.*, 2008). MM research is still a new and complex concept (Lowenthal and Leech, 2010, Evan *et al.*, 2011), although there is increasing evidence of its use in health and social sciences but with limited acceptable use of conceptual or theoretical frameworks to guide lines of inquiry (Morgan, 2007; Evans *et al.*, 2011). However, researchers continue to seek advice on deciding on what methodology would be more appropriate for their study (Morgan, 2007; Bergman, 2011).

This chapter discusses MM as the main methodology employed in this thesis for the two primary studies (Chapters Five and Six). Because MM is a combination of both quantitative and qualitative methodologies (Happ, 2009; Johnson *et al.*, 2007), a brief description of each will be offered, including past and contemporary writers as both eras are relevant to this chapter. The historical evolution of MM and its relevance to health and social sciences is highlighted, signposting it as a pragmatic research methodology, which was most appropriate for this research to answer specific research questions, rather than restricting or constraining the researcher's choices (Johnson and Onwuegbuzie, 2004). The justifications for adopting Morgan (2007)'s Pragmatic Framework as the conceptual framework as well as the rationale for using the MM approach in combination with

systematic reviews are discussed. The critiques for using mixed methodology in general, and Morgan's Pragmatic Framework in particular to address the research questions are also offered. The sequence of the methodological approaches used in this thesis is outlined as follows:

- systematic reviews,
- cross-sectional general practice survey, using both qualitative and quantitative methods, and
- participatory research, using qualitative methods.

The primary aim of the research study is to develop an in-depth understanding of how culturally-competent diabetes care services can be delivered to the needs of EMGs with diabetes. The chapter concludes by presenting the strengths and limitations of choosing this mixed methodology.

Before proceeding to the discourse, it is important to clarify the distinction between key definitions as used throughout the thesis.

4.2. Quantitative and qualitative research methodologies: Definitions, differences, historical evolution and application in health sciences

Mixed methodology, commonly referred in this chapter as MM is currently regarded as one of the emerging and leading research methods where mixing methods and types of data requires new sets of skills and sensibilities (Creswell and Plano Clark, 2007; Bergman, 2011). However, in order to comprehend MM, it is important to offer a brief definition/description of qualitative and quantitative research methodologies and concepts as used throughout this thesis.

Quantitative research is often contrasted with qualitative research (and vice versa), which often turned into a 'paradigm war,' resulting in apparently incompatible worldviews underlying the two methodologies (Pope and Mays, 2006; Pearson *et al.*, 2007; Manning & McMurray, 2010). Researchers view each methodology differently with some claiming dominance of either methodology. On one hand, Cohen (1980) views quantitative research methodology as a social research that employs empirical methods and empirical statements, whereby the latter are descriptive and relate to what 'is' the case in the 'real world' rather than what "ought" to be the case. On the other hand, quantitative research methodology is viewed as a type of research that explains a particular phenomenon by collecting numerical data that are analysed using mathematical methods, in particular statistics (Creswell, 1994) or adhering 'to a set of sequential steps to acquire dependable data' (Pearson *et al.*, 2007:43). Data collected from this methodology are used to control the phenomenon with the focus on theory testing (derived from previous research to formulate a hypothesis or testable idea), prediction and control (Pearson *et al.*, 2007). In addition, the hypothesis is then tested using objective methods, a process called deduction. Approaches related to this methodology include experimental research, survey research, and cohort research studies. Quantitative research attempts to answer questions such as, 'how big is X or how many X's are there?' (Pope and Mays, 2006: 3) The General Practice Survey proposed in this research (Chapter Five) will attempt to use this method to investigate diabetes primary care service provision to EMGs in a typical ethnically mixed medium-sized city.

In the traditional sense, quantitative research methodologies continue to be the driving force behind evidence-based practice and research, with the ability to measure and quantify a phenomenon, as well as the relationships between phenomena numerically,

whether the phenomenon is health, biological, behavioural, economic, or emotional in scope (Vance *et al.*, 2013). Bourgeault *et al.* (2010) demonstrated that each methodology (quantitative and qualitative) has benefits in its own right in health and social sectors. In this research, this researcher will employ both quantitative methods to understand, for example, the prevalence of diabetes rates in EMGs as well as qualitative methods to uncover staff's lived perspectives of the cultural barriers faced in their day-to-day interactions with the patients from EMGs. In addition, quantitative researchers have focused on determining cost-effectiveness, looking at the number of patients with specific chronic diseases, such as diabetes and the cost of treating these patients on an annual basis. This approach is widely valued by most healthcare organisations. For example, the National Institute for Health and Care Excellence (NICE), uses quantitative evidence to develop guidelines and make recommendations on the effectiveness of treatments and medical procedures for different diseases taking into consideration both desired medical outcomes and also economic arguments regarding different treatments (NICE, 2009). However, quantitative approaches do not often take into account the patient perspective; therefore, qualitative research methodologies are required to understand the patient perspectives, their satisfaction level and coping strategies with the disease and treatment regimens to ensure concordance (Creswell and Plano Clark, 2007; Mayberry and Osborn, 2012). For instance, cultural barriers such as commitments to religious beliefs cannot be fully understood by quantitative methods alone. Qualitative research is also needed to enrich understanding in this area, and mixed method could do even better, which further supports the rationale for choosing MM for this research.

In contrast, Roberts and Priest (2010:151) view qualitative research methodology as '*a means of exploring an area of human experience, in order to try to understand how humans make sense of their world. It allows us to identify and describe topics or*

phenomena about which little is known, and explore and explain the scope and meaning of such phenomena.' This is concurred by Pope and Mays (2006), who add that qualitative researchers strive to interpret social phenomena (such as interactions and behaviours) in terms of the meanings people attach to them. They refer to this as interpretative research methodology and conclusions are drawn from the information obtained from participants, which may generate new hypotheses or theories, a process termed induction (Roberts and Priest, 2010). Qualitative research is mostly used to study people, human phenomena and the process of carrying out the research itself. The type of questions usually answered by this methodology include: *'what is X, and how does X vary in different circumstances, and why?'* (Pope and Mays, 2006:3). Examples of methods used in qualitative methodology include: participant observation, interviews, case studies, and ethnographic research. Qualitative methodology has been seen as a vital instrument for evaluating policies, reforms and programs, analysing how healthcare professionals deal with profound changes in their work, exploring people's unique experiences, views, opinions, studying different cultures, grasping the complexity of the phenomenon, and understanding issues in their natural settings. In addition, randomised controlled trials (RCTs) can also be carried out using nested qualitative studies aimed at understanding different research results being produced, the why and how they worked or did not (Sturt *et al.*, 2008).

Quantitative and Qualitative research methodologies tend to differ in major steps in every research process (Table 4.1), such as the intent of the study, review of the literature, use of the questions or hypotheses, data collection and analysis, researchers' roles, and validation of the data (Creswell and Plano Clark, 2007).

Table 4.1: Elements of quantitative and qualitative research in the process of research adapted from Creswell and Plano Clark (2007:29)

Elements of qualitative research tend towards...	Process of research	Elements of quantitative research tend towards...
<ul style="list-style-type: none"> • Understands meaning individuals give to a phenomenon inductively 	Intent of the research	<ul style="list-style-type: none"> • Test a theory deductively to support or refute it
<ul style="list-style-type: none"> • Minor role • Justifies problem 	How literature is used	<ul style="list-style-type: none"> • Major role • Justifies problem • Identifies questions and hypotheses
<ul style="list-style-type: none"> • Ask open-ended questions • Understand the complexity of a single idea (or phenomenon) 	How intent is focused	<ul style="list-style-type: none"> • Ask closed-ended questions • Test specific variables that form hypotheses or questions
<ul style="list-style-type: none"> • Words and images • From a few participants at a few research sites • Studying participants at their location 	How data are collected	<ul style="list-style-type: none"> • Numbers • From many participants at many research sites • Sending or administering instruments to participants
<ul style="list-style-type: none"> • Text or images analysis • Themes • Larger patterns or generalisations 	How data are analysed	<ul style="list-style-type: none"> • Numerical statistical analysis • Rejecting hypotheses or determining effect sizes
<ul style="list-style-type: none"> • Identifies personal stance • Reports bias 	Role of the researcher	<ul style="list-style-type: none"> • Remains in the background • Takes steps to remove bias
<ul style="list-style-type: none"> • Using validity procedures that rely on the participants, the researcher or the reader 	How data are validated	<ul style="list-style-type: none"> • Using validity procedures based on external standards, such as judges, past research, statistics.

4.3. Quantitative and Qualitative Research Paradigms

The ideological differences between quantitative and qualitative research led to the debate about 'paradigm differences' whereby they were seen as incompatible and argumentative factions. Paradigm was originated from ancient philosophy and continue to be present (Tashakkor and Teddlie, 2010). According to Pearson et al. (2007: 38) a paradigm is 'a

generally accepted world view or philosophy, a structure within which theories of the discipline are organised,' which consist of basic beliefs about a particular phenomenon. As a result of these ideological differences between quantitative and qualitative research paradigms, two fundamentally different worldviews have emerged; positivist (sometimes called 'realist' paradigm (concerned with quantitative worldview) and constructivist, sometimes called subjectivist (aligning to the qualitative worldview).

Both quantitative and qualitative paradigms have a long history in western thought; with the quantitative paradigm approach dating far back to Plato and Aristotle eras as evident in the work of Descartes and Newton (Pearson *et al.*, 2007). The qualitative paradigm can be traced back from the work of Alfred Schutz, an Austrian sociologist-philosopher (1899 - 1959), who argued for a distinction between natural and social sciences (Pearson *et al.*, 2007) and continued by others [such as the two American sociologists, Barney Glaser (1930-present) and Anselm Strauss (1916-1996), the founders of the Grounded Theory], who argued that much of the current research is predominantly about verifying theory or developing theory through logical deduction rather than from the experimental data itself, thereby advocating the view that 'the adequacy of a theory can't be divorced from the process of creating it (Glaser and Strauss, 1967: 5). However, the quantitative paradigms continued to be dominant over qualitative paradigms and remain the most popularly used in health sciences. In fact, most western health care systems highly value the positivist paradigm, with some healthcare professionals considering it as the only legitimate framework for health research (Pearson *et al.*, 2007). Notwithstanding, many questions remained unanswered since positivist paradigm cannot examine the social aspects of human life and the lived experience in natural setting, which is the essence of the constructivism paradigm (Pearson *et al.*, 2007; Creswell and Plano Clark, 2007).

There are a number of distinct differences that have been used to polarise these two paradigms, documented by Manning and McMurray (2010), adapted from Gall *et al.* (1996), and Neuman (2006), which are presented in Table 4.2.

Table 4.2: Comparative differences between quantitative and qualitative researchers: adapted from Neuman (2006) and Gall, Borg & Gall (1996) in Manning and McMurray (2010:10)

Quantitative researchers	Qualitative researchers
Assume an objective social reality that exists independent of the observer	Assume that reality is jointly constructed and arises out of social interaction shared by the participants
Pursue a set of explanatory laws that are fixed and universal in their application	Aim at in-depth description of a dynamic reality that is contextually based
Take an objective, detached stance towards research participants and their setting in order to ensure their data are value-free	Acknowledge that all perceptions are value-laden and accordingly often get up-front and personal with their informants
Collect reliable and valid data that are population based and therefore generalizable	Collect rich and detailed data that reflect the lived experience of their subjects
Formulate hypotheses that are empirically testable	Generate research questions that are designed to be interpretive in nature
Study behaviour and other observable phenomena	Study the meanings that individuals impute to their everyday experience
Strive for generalisations that assist in the understanding, explanation, prediction of human behaviour	Strive for uniqueness in the understanding of human behaviour in natural settings
Emphasise precision, control and reductionism	Focus on rich description with a view to developing shared understandings
Use preconceived theories and operationalised concepts to determine what data will be collected	Develop concepts and models often in concert with the data collection phase
Collect numerical data that depict the social environment	Assemble verbal and pictorial data to help interpret the social environment
Use statistical methods to analyse data	Use analytic induction to analyse data
Make use of statistical inference techniques to generalise findings from a sample to a defined population	Leave it to the consumer to make cautious generalisations from one population to another based on identical elements in both contexts.
Prepare impersonal, objective reports of research findings	Prepare interpretive reports that reflect researchers' constructions of the data and awareness that readers will form their own constructions from what is reported.

Although most of these ideological differences between qualitative and quantitative researchers (Table 4.2) have existed for over a century, the ignition point of the debate commenced in the 1970s when postmodernism became accepted (Evans *et al.*, 2011). As a result of 'paradigm wars', researchers questioned whether or not qualitative and

quantitative data could be combined; for example, Guba, 1990; Tashakkori and Teddlie, 1998. The dichotomies between the deductive–objective–generalizing approach and inductive–subjective–contextual approach (Morgan, 2007) continue to exist in some camps, with some researchers now choosing to integrate these methodologies into one paradigm (Tashakkori and Teddlie, 1998; Johnson and Onwuegbuzie, 2004; Johnson *et al.*, 2007; Evans *et al.*, 2011) leading to a third paradigm, called MM.

Based on this researcher's observations in practice, there remains an uneasy balance between the two paradigms, with qualitative research still seen as the 'poorer cousin' as funding organisations continue to favour quantitative studies, viewing these studies as from a superior methodology. This is demonstrated in clinical trials where more quantitative research compared to qualitative research is used and at times, clinical trials would use MM (Sturt *et al.*, 2008). The question is: *'What does MM research offer to improve knowledge of clinical trials and science in general?'*

4.4. Mixed methods (MM)

Mixed method research is a research design with a methodology and methods (Creswell and Plano Clark, 2007:18), which represents a social science research approach that encourages the integration of both quantitative and qualitative methodologies (Morgan, 2007; Symonds and Gorard, 2010). As a methodology, it deals with philosophical assumptions that guide the direction of the collection and analysis of data and mixture of quantitative and qualitative approaches in many phases in the research process, from the initial philosophical assumptions to the drawing of conclusions. As a method, it focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or series of studies. Its fundamental premise is that the use of quantitative and qualitative

approaches in combination should provide a better understanding of research problems than either approach alone.

This definition is identical to the one proposed by (Johnson *et al.*, 2007:118) following detailed review of different MM researchers' perspectives:

'Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purpose of breadth and depth of understanding and corroboration.'

Mixed methodology has emerged as a 'third paradigm,' (often called the 'pragmatist paradigm', 'third wave' or 'third research movement'), for social and health sciences research that has moved past the paradigm wars and has developed a platform of ideas and practices that are practical, plausible and distinct and that mark the approach out as a viable alternative to quantitative and qualitative paradigms (Johnson and Onwuegbuzie, 2004; Denscombe, 2008). However, there are also a number of variations within the MM approach that should not be disregarded (Denscombe, 2008; Tashakkor and Teddlie, 2010). Such variations must not be ignored, therefore, it is important to draw attention to the way in which the notion of 'research paradigm' could '*accommodate a level of variation and inconsistency in its ideas and practices - treating them not as some kind of aberration or short-term problem that needs to be resolved, but as an ongoing and inherent feature of the paradigm itself (Denscombe, 2008:2)*'. Greene (2008:20) views MM as '*an orientation towards social inquiry that actively invites us to participate in dialogue about multiple ways of seeing and hearing, multiple ways of making sense of the social world, and multiple*

standpoints on what is important and to be valued and cherished.' Johnson and Onwuegbuzie (2004:17) define MM research as *'the class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study.'* This definition is also in line with the one earlier proposed by Creswell and Plano Clark (2007). The contention behind all these authors is the quest for mixing and combining quantitative and qualitative methodologies, (whilst acknowledging their limitations) to answer specific research questions.

4.5. Historical evolution of mixed methods

The historical overview of MM helps to address some of the lingering debates and issues relating to designing and conducting MM studies and set out a clear philosophical basis for choosing the design for this PhD thesis. Creswell and Plano Clark (2007) summarise MM history into four overlapping periods (Table 4.3). The origins of MM research can be traced to its use among fieldwork sociologists and cultural anthropologists in the early 20th century (Johnson *et al.*, 2007: 113). Writers who have attempted to put a chronological time-line to its evolution as a research paradigm have tended to place it against a backdrop of the 'paradigm wars' (Denscombe, 2008). Although there has not been complete agreement about the dates, its emergence is seen around the era when the positivist paradigm (linked with quantitative methodologies discussed above) was dominant (1950s to mid-1970s) but changed to an era in which the constructivist research paradigm (linked with the qualitative methodologies) became established as a feasible alternative (mid-1970s to 1990s) (Plano Clark, 2007; Denscombe, 2008). Besides the contributions of Campbell and Fiske (1959) in the formative period, MM research paradigm is seen as emerging from the 1990s onwards, establishing itself alongside the previous paradigms as the third apparent paradigm with quantitative and qualitative research

flourishing and coexisting (Johnson *et al.*, 2007, Denscombe, 2008; Tashakkori and Teddlie, 2010).

Table 4.3: Selected writers important in the development of mixed methods research and their contributions, adapted from (Creswell and Plano Clark, 2007:14)

Stage of development	Author (Year)	Contribution to mixed methods research
Formative period (1950s-1980s)	Campbell and Fiske (1959)	Introduced the use of multiple qualitative methods to study the validation of psychological traits
	Sieber (1973)	Combined survey and interviews
	Jick (1979)	Discussed triangulating quantitative and qualitative data
	Cook and Reichardt (1979)	Presented 10 ways to combine quantitative and qualitative data
Paradigm debate period (1970s-1990s)	Rossmann and Wilson (1985)	Discussed stances towards combining methods – purists, situationalists and pragmatists
	Bryman (1998)	Reviewed the debate and established connections within the two traditions
	Reichardt and Rallis (1994)	Discussed the paradigm debate and reconciled the two traditions
	Greene and Caracelli (1997)	Suggested that we move past the paradigm debate
Procedural development period (late 1980s-2000)	Greene, Caracelli, and Graham (1989)	Identifies a classification system of types of MM designs
	Brewer and Hunter (1989)	Focused on the multi-method approach as used in the process of research
	Morse (1991)	Developed a notation system to convey how quantitative and qualitative components of a study are implemented
	Creswell (1994)	Identified three types of MM designs and found studies that illustrated each type
	Morgan (1998)	Developed a typology for determining design to use
	Newman and Benz (1998)	Provided an overview for the procedures
	Tashakkori and Teddlie (1998)	Presented topical overview of MM research
	Bamberger (2000)	Provided an international policy focus to MM research
Advocacy as a separate design period (2003-present)	Tashakkori and Teddlie (2003)	Provided a comprehensive treatment of many aspects of MM research
	Creswell (2003)	Compared quantitative, qualitative, and MM approaches in the process of research
	Johnson and Onwuegbuzie (2004)	Positioned MM research as a natural complement to traditional quantitative and qualitative research.

Notable MM works from some researchers in the 1990s, (e.g. Julia Brannen, Alan Bryman, Burke Johnson, Anthony Onwuegbuzie, Jennifer Greene, John Creswell, Abbas Tashakkori, Charles Teddlie), have provided vital procedural guidelines, such as vocabulary, taxonomy, and process description, seen by many as successful (Bergman, 2011; Evans *et al.*, 2011; Creswell and Plano Clark, 2007). Part of the success is attributed to the adoption of division of labour between quantitative and qualitative methods (Bergman, 2011). In fact, the distinctive nature of the MM approach and the core ideas and practices on which the MM paradigm stands are explicitly depicted in the works of some writers such as Creswell (2003), Creswell and Plano Clark (2007) and Tashakkori & Teddlie (1998, 2010). According to Denscombe (2008), these MM writers have contrasted the MM approach with research paradigms that have favoured the use of either quantitative or qualitative methodologies, and they have argued that the defining characteristics of the MM approach involve its use of:

- 1) quantitative and qualitative methods within the same research project;
- 2) a research design that clearly specifies the sequencing [quantitative/qualitative] and qualitative/ quantitative] and priority that is given to the quantitative and qualitative elements of data collection and analysis;
- 3) an explicit account of the manner in which the quantitative and qualitative aspects of the research relate to each other, with increased emphasis on the manner in which triangulation is used; and
- 4) pragmatism as the philosophical underpinning for the research.

These defining characteristics have been portrayed in the DEDICATED study using pragmatism as the philosophical underpinning of the work.

4.6. Pragmatic paradigm worldviews

The historical emergence of MM paradigm has led to some researchers regarding it as an integrative methodology (Creswell, 2007; Evans *et al.*, 2011). The integrative methodology is in line with pragmatism, where the focus is on the problem in its social and historical context rather than on the method (Evans *et al.*, 2011). Although the issue of reconciling paradigms remains apparent, pragmatism has been embraced as the best philosophical foundation for MM research (Tashakkori and Teddlie, 2010) and the use of different paradigms in MM research, whilst ensuring that each paradigm is honoured in its own right and made explicit when each of them is used (Greene and Caracelli, 1997). In fact, there appears to be a consensus within the field of MM research that the adoption of a mixed methodology approach has to be pragmatic where the philosophical assumption or convictions *‘should be driven by the very questions that the research seeks to answer’* (Tashakkori and Teddlie, 2010:96). This view is shared by Creswell (2003), whereby pragmatists link the choice of research approach directly to the purpose and nature of the research questions posed. Unsurprisingly, Armitage (2007:3) contends that *‘research should be multi-purpose and based on a what works tactic, which allows the researcher to address questions that do not sit comfortably within a wholly quantitative or qualitative approach to design and methodology.’* However, researchers need to have the training/understanding to reach this realisation. This researcher attended one-week training on ‘mixed methods reviewing course’ offered by both his University and external provider (a Professor in mixed methods approaches from the University of Toronto), which enhanced his knowledge and skills embarking in this methodology.

The pragmatic paradigm has been described as having an intuitive appeal (permission to study areas that are of interest), embracing methods that are appropriate and using findings in a positive manner in harmony with the value system held by the researcher

(Tashakkori and Teddlie, 1998; Creswell, 2003; Armitage, 2007). It is contended that its logic of inquiry which includes the use of induction (or discovery of patterns), deduction (testing of theories and hypotheses), and abduction (uncovering and relying on the best of a set of explanations for understanding one's results) (De Waal, 2001; Morgan, 2007), makes it more appealing to researchers as many research questions and combinations of questions are best and most fully answered through mixed research solutions (Johnson and Onwuegbuzie, 2004).

This thesis will use Morgan's (2007) Pragmatic Framework as the theoretical framework.

4.7. Morgan's Pragmatic Framework Approach to Methodology in Social Sciences

David L. Morgan, a Professor of Liberal Arts and Sciences at Portland State University, recommends an organisational framework (Table 4.4) for understanding his pragmatic approach to social science methodology. The part of his framework relevant in this study relates to *'key issues in social science research methodology, rather than the metaphysical paradigm's emphasis on abstract issues in the philosophy of knowledge (Morgan, 2007:70).'* These key issues or concepts (described below) enable understanding of his pragmatic approach to social science methodology, which have also been useful in this study. According to Tashakkori and Teddlie (2010:14), the Morgan (2007) framework refers to key 'pragmatic concepts' such as abduction, intersubjectivity, and transferability, which supersede the quantitative / qualitative dichotomies of induction/deduction, subjectivity/objectivity, and context/generality' which Morgan (2007:73) himself finds helpful to think of *'Qualitative Research as research that emphasizes an inductive–subjective–contextual approach, whereas Quantitative Research*

emphasizes a deductive–objective–generalizing approach. Where we encounter problems is by treating these broad tendencies as absolute, defining characteristics for these two different approaches, and these problems become even worse when we deny the possibility of working back and forth between the two extremes. Fortunately, the pragmatic approach offers an effective alternative through its emphasis on the abductive–intersubjective–transferable aspects of our research.'

In essence, Morgan (2007) argues that the usual forced dichotomy between subjective and objective (Table 4.4) is an equally artificial summary of the relationship between the researcher and the research process. Morgan suggests that there is nothing like 'complete objectivity,' and neither is it possible to have 'complete subjectivity.' Thus, he recommends that 'any practicing researcher has to work back and forth between various frames of reference, and the classic pragmatic emphasis on an *intersubjective* approach captures this duality'. Undoubtedly, this dimension places emphasis on processes of communication and shared meaning that are central to any pragmatic approach.

According to Morgan, intersubjectivity also represents the pragmatic response to issues of incommensurability. In a pragmatic approach, there is no problem with asserting both that there is a single 'real world' and that all individuals have their own unique interpretations of that world. Rather than treating incommensurability as an all-or-nothing barrier between mutual understanding, pragmatists treat issues of intersubjectivity as a key element of social life. Here, it can be seen that the pragmatist emphasis on creating knowledge through lines of action points to the kinds of 'joint actions' or 'projects' that different people or groups can accomplish together.

Morgan's final duality (Table 4.4) makes a fundamental distinction between knowledge that is either specific and context-dependent or universal and generalised. As Morgan (2007:72) himself puts it, *'the pragmatic approach once again rejects the need to choose between a pair of extremes where research results are either completely specific to a particular context or an instance of some more generalised set of principles,... as the research results can never be either so unique that they have no implications whatsoever for other actors in other settings or so generalised that they apply in every possible historical and cultural setting.'* From a pragmatic view point, what is vital is the extent to which researchers take learning by using one type of method in one specific setting and make the most appropriate use of that knowledge in other circumstances. This requires the process of working back and forth, in this case between specific results and their more general implications (Morgan, 2007).

Whilst Morgan is mindful of the different meanings of the concepts (such as induction and deduction, subjectivity and objectivity, or context and generality), he believes that an emphasis on abduction, intersubjectivity, and transferability would generate 'a range of new opportunities for thinking about classic methodological issues in the social sciences (Morgan, 2007:72).' Denscombe (2008) supports Morgan's (2007) account of his framework. He further suggests that the MM approaches might benefit from pragmatism as it allows it to incorporate variations and inconsistencies evident within the approach.

Table 4.4: A Pragmatic Alternative to the Key Issues in Social Science Research Methodology (adapted from Morgan 2007:71)

Dichotomies	Qualitative approach	Quantitative approach	Pragmatic approach
Connection of theory and data	Induction	Deduction	Abduction
Relationship to research process	Subjectivity	Objectivity	Intersubjectivity
Inference from data	Context	Generality	Transferability

+ The columns represent the main comparative distinctions, contrasting a pragmatic approach with quantitative and qualitative research. The rows make comparisons in terms of usual 3 choices often used.

4.8. Strengths and limitations of the pragmatist paradigm

The discussion so far has mostly illustrated the advantages of using the mixed methodology paradigm and how pragmatists value both qualitative and quantitative research methodologies as important and relevant in answering research questions in social and health sciences and for complementing each other. In fact, MM researchers argue that MM should not be used to replace either of these two approaches but should be seen as enhancing strengths and reducing weaknesses of both in a single research study and across studies, implying categorically that this third school of thought (pragmatist paradigm) could be at the centre with qualitative and quantitative research sitting on its left and right hand side respectively (Johnson and Onwuegbuzie, 2004). It is unsurprising that some writers favoured this intuitive appeal that the pragmatist paradigm should be seen as a way forward for researchers to bridge the rift between qualitative and quantitative research in clinical practice, so as to increase the rigour of the research results (Onwuegbuzie and Leech, 2005; Creswell and Plano Clark, 2007). The usefulness of MM as a pragmatic paradigm to this research has been further illustrated in the 'justification section' below.

Although pragmatism has been endorsed as a philosophy that can help to build bridges between conflicting philosophies, it also has shortcomings. Firstly, basic research may be affected and viewed as producing less immediate and practical results when compared with applied research (Johnson and Onwuegbuzie, 2004). However, the essence for the researcher is to consider the research question being addressed and the value it is likely to add to the body of knowledge. Secondly, researchers from the transformative-emancipatory framework have suggested that pragmatic researchers sometimes fail to provide satisfactory answers to the questions, such as ‘for whom is a pragmatic solution useful?’ (Mertens, 2003; Johnson and Onwuegbuzie, 2004). Although they consider this as a weakness, it could also be a strength as using pragmatism in this research will add knowledge and value to existing literature rather than if it was purely restricted to either qualitative or quantitative methodologies.

Thirdly, another pitfall of using pragmatism relates to interpretations. For example, what might mean usefulness or workability can be vague unless explicitly addressed by the researcher. Johnson and Onwuegbuzie (2004:19) ascertain that *‘pragmatic theories of truth usually have difficulty dealing with the cases of usefulness but non-true beliefs or propositions and non-useful but true beliefs or propositions.’*

Whilst these weaknesses of pragmatism remain unchallenged by prominent writers in the field, (such as Bronwynne Evans, Jennifer Greene, John Creswell, Abbas Tashakkori, Charles Teddlie Martyn, David Morgan), researchers sometimes used MM pragmatically as a means to avoid biases inherent to single-method approaches (Denscombe, 2008), thereby compensating specific strengths and weaknesses associated with particular methods. In effect, the DEDICATED study adopted MM because of the considerable advantages compared to monomethod research as it is the most appropriate methodology

to address the primary research question to better understand the phenomenon being investigated. Furthermore, it was considered that it would cross-validate or complement individual findings from the four proposed studies, by combining different strands of knowledge, skills, and disciplines to improve validity of the findings (Creswell, 2003; Bergman, 2011).

4.9. Justifications for using pragmatic methodology

In this section, the rationale for adopting systematic reviews and MM as the pragmatic research methodology for this PhD thesis is articulated. This decision is based on three key issues; first, the methodological limitations around existing work within the field of research on 'Delivering diabetes care to EMGs' within the chosen location, secondly, the researcher's pragmatic philosophical stance to ensure that the chosen topic is better understood by diabetes service providers. Thirdly, the interest in Morgan's pragmatic framework approach to methodology in the Social Sciences (2007). In fact, the Morgan's framework to methodology advocates a 'pragmatic approach' as a new guiding paradigm, both as a basis for supporting work that combines qualitative and quantitative methods and as a way to redirect researchers' attention to methodology rather than metaphysical concerns (epistemological stances), which is concordant with this study. Further underlying motivations and reasons for selecting this approach are placed within the historical overview of MM and the debates around the 'paradigm differences' as discussed above.

To further comprehend the rationale for choosing this methodology, it is essential to consider the research questions for this thesis and the sequence of the methodological approaches, summarised in Figure 4.1 below. The primary research question is: How could NHS health care professionals work with EMGs in primary care to provide effective

culturally-competent care and services tailored to the needs of EMGs with diabetes? This question is further underpinned and informed by the additional questions:

1. What are the cultural barriers to people with diabetes from EMGs in accessing effective diabetes care services
2. What is the impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in EMGs
3. What is the diabetes primary care service provision for EMGs and how are these services commissioned in a typical medium sized UK ethnically mixed city?
4. Using evidence from questions 1-3 above, how can an effective culturally-competent diabetes care service be designed and implemented in primary care for EMGs with diabetes?
5. What are the national and international practice and policy recommendations to promote the designing and implementation of effective culturally competent services to meet the needs of EMGs with diabetes?

The first four research questions, which are linked, are considered to each constitute standalone studies, which would be reported as individual chapters. Question 5 represents the recommendations arising from all the studies. In considering the most appropriate paradigm to select, these research questions were taken into account. First and foremost, the relevance of the positivist paradigm was considered, whilst reflecting upon the existing knowledge of cultural barriers and culturally-competent diabetes-related interventions for ethnic minority people with diabetes and the research gaps found in the scoping and literature reviews. It can be evident that positivist paradigm may only partly address some of the research questions, such as question 1 (Chapter Two), where a systematic review included studies of relevant designs, (quantitative or qualitative or mixed methods), in the analysis to identify and explore cultural barriers impeding EMGs with diabetes from

accessing effective diabetes care services. The second systematic review (Chapter Three) included relevant quantitative and qualitative study designs reporting on any culturally-competent intervention to examine the impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in EMGs. Although these different study designs were included to answer these two questions, the heterogeneous nature of the included studies required a narrative analysis, which is often associated with the constructivist paradigm. It can be seen that the narrative data analyses in both reviews are in line with pragmatist philosophy of mixing in ways that offer the best opportunities for answering important research questions (Johnson and Onwuegbuzie, 2004).

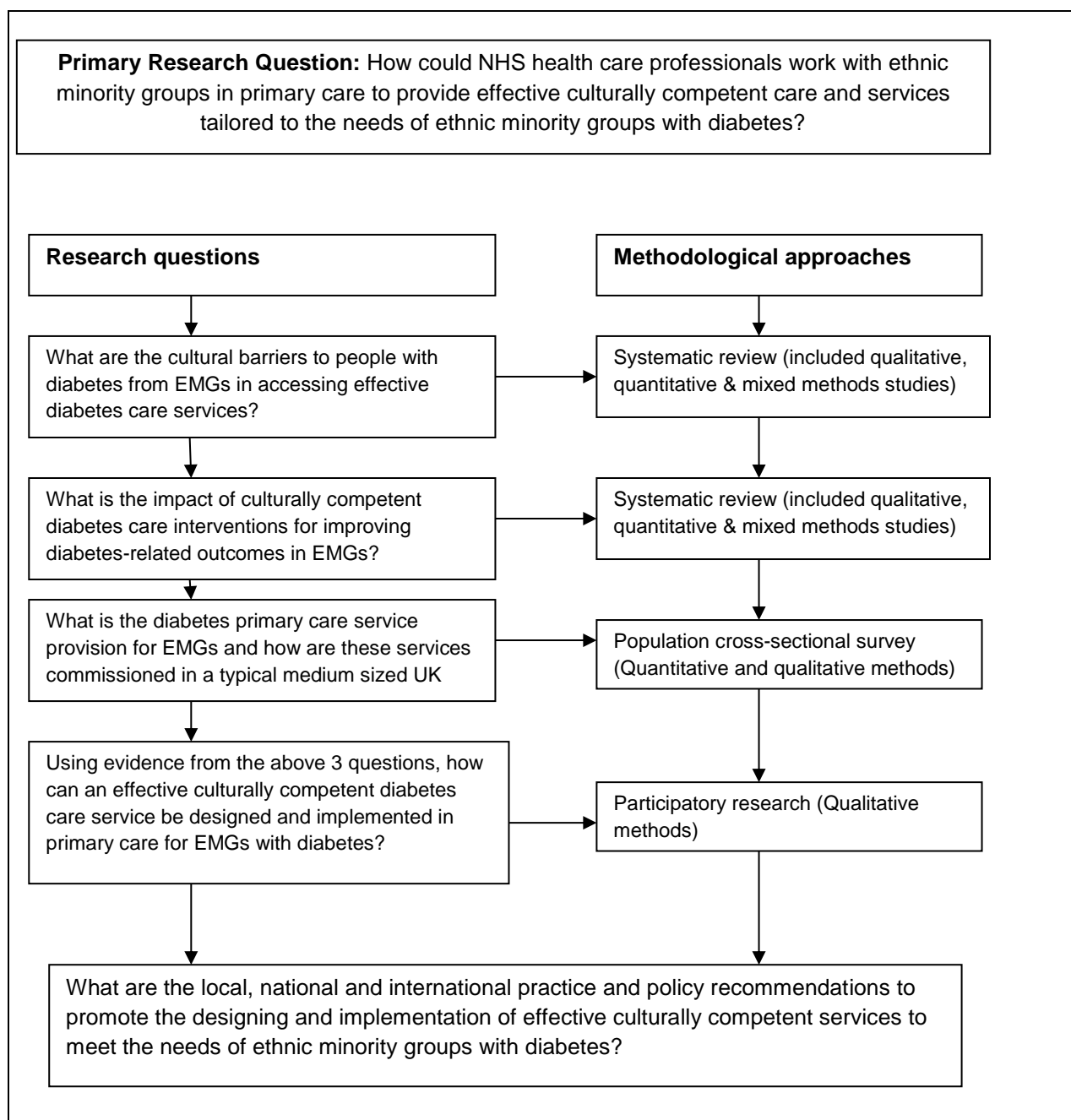
The use of mono-methodology which is underpinned by positivist or constructivist paradigms could not fully address these two questions. In study 3, which addresses research question 3 (Chapter Five), a positivist paradigm via a population survey method, including a structured survey comprising mostly closed questions, was considered to be most appropriate to address the research questions. However, in the data analysis, the constructivist paradigm approach would be adapted to thematically analyse part of the data, such as describing the various cultural barriers that may be reported by staff in the questionnaire, to bring out the lived experiences of staff to these cultural barriers in their daily interactions with ethnic minority patients. Therefore, the use of the positivist paradigm alone to examine the social aspects of human life and the lived experience cannot completely address the research question (Pearson *et al.*, 2007). This implies that the pragmatism worldview of MM was considered to facilitate the full exploration of this question by mapping out how much culturally-competent diabetes care services are being delivered within Coventry from participating general practices.

Based on the evidence likely to emerge from the first 2 studies (questions 1-2), in addition to study 3, it was considered that there would be sufficient evidence to investigate how an effective culturally-competent diabetes care service can be designed and implemented in primary care for EMGs with diabetes to bridge the gaps emerging from the existing literature. The constructivist paradigm would attempt to explore the social context and the lived experiences of both patients and general practice staff in their natural settings (Pope and Mays, 2006; Pearson *et al.*, 2007). This methodology can be used to examine what could be done to improve the social aspects and lived experiences regarding cultural and linguistic barriers impeding access to effective diabetes care services. The same constructivist paradigm was considered to address research question 4, facilitated by a participatory research design, constituting Chapter Six. However, descriptive statistics may be used in addition to qualitative methods, to analyse data, such as the characteristics of participants (number of participants, participants' attendance rates, and average age of participants), which are associated with the positivist paradigm, thereby validating the constructivist paradigm on the same social phenomena (Pope and Mays, 2006). Therefore, it can be seen that the constructivist paradigm alone cannot completely address this research question, which the pragmatist paradigm would aid in the research process.

To address question 5 above, a combination of both positivist and constructivist paradigms was considered to reflect upon all the evidence and gaps identified in the four studies used (questions 1-4 above). This evidence should provide the national and international practice and policy recommendations that would promote the designing and implementation of effective culturally competent services to meet the needs of EMGs with diabetes. The combination of these two paradigms is pragmatic, by combining all the evidence from the research questions to address the primary research question. Therefore, this researcher would contend that in considering the three paradigms (positivist, constructivist, and

pragmatist), the use of a mixed methodology proposed within this research process is appropriate as it is based on a rationale of making a number of pragmatic decisions in line with Morgan's Pragmatic Approach to Methodology in the Social Sciences (Morgan, 2007). This methodological approach will inform the primary research question: '*How could NHS health care professionals (HCPs) work with EMGs in primary care to provide effective culturally-competent care and services tailored to the needs of EMGs with diabetes?*' in addition to the sub research questions. It is worth noting that both the positivist and constructivist paradigms complement each other where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a workable solution in this single study, which are concordant with the pragmatist paradigm (Johnson and Onwuegbuzie, 2004; Morgan, 2007).

Figure 4.1: Flow diagram of the thesis methodological approaches



4.10. Data analysis of the research study

Due to the nature of the data to be collected in this research study, both descriptive statistical and appropriate qualitative approaches will be used for data analysis. These approaches will be discussed within individual studies.

4.11. Chapter summary

This chapter has signposted the methodology for the DEDICATED research study. It demonstrated that quantitative and qualitative research belong to different paradigms, underpinned by different philosophical positions, address different research themes and questions, differ in their data collection and data analysis methods, and demand different interpretations of their respective research results (Bergman, 2011). Mixed methodology was selected for this study, and it will sometimes apply both quantitative/qualitative or quantitative or qualitative techniques within one study to address one research question, which is the essence of pragmatism. This methodology has worked well in previous research studies (Greenhalgh *et al.*, 2006; Lloyd *et al.*, 2008; Sturt *et al.*, 2008), and it will complement the DEDICATED research study, in order to reach a better understanding of the investigated phenomenon, with the aim to influence practice positively. This chapter has also examined the advantages and disadvantages of using MM, with this researcher supporting the use of MM as it has potential to examine both the subjective and objective of the studied phenomenon. The detailed research methods of the four proposed studies listed above will be presented within each chapter.

CHAPTER FIVE

DELIVERING DIABETES CARE TO ETHNIC MINORITY POPULATIONS - A SINGLE CITY CASE STUDY

5.0. Abstract

Objective: Two systematic reviews conducted by this researcher have demonstrated (a) cultural barriers to diabetes service uptake across international multi-ethnic populations, and (b) effective interventions to reduce these cultural barriers. The principal aim of this study was to investigate diabetes primary care service provision to ethnic minority groups (EMGs) and commissioning of such services in a typical ethnically mixed medium-sized UK city with 4.4% diabetes prevalence.

Research methods: A semi-structured survey comprising 35 questions was carried out across all 66 General Practices in Coventry between November 2011 and January 2012 using population survey methods. Data were analysed using descriptive statistics. The survey examined the cultural competence of diabetes services using the Culturally-Competent Assessment Tool (CCAT).

Results: 34 practices responded (52%). Six important findings emerged:

- 1) 94% of general practices numerically reported the ethnicity of their populations in broad categories.
- 2) One in three people of the diabetic population prevalence compared with 1 in 5 staff was from an ethnic minority group.
- 3) Nine (26%) practices reported over 50% diabetes prevalence in EMGs; the highest practice had 96% EMGs with diabetes amongst the diabetic population.
- 4) 56% of practices delivered culturally-competent diabetes services scoring 90%-100%, 26% scored 70%-89% on the CCAT. Eighteen percent delivered a lower number of culturally-competent services (<70%).
- 5) Ten practices (29%) reported better utilisation of diabetes annual checks in the majority white British population compared to EMGs.
- 6) Cultural diversity in relation to language and strong traditions around food were most commonly reported as barriers to culturally-competent service delivery.

Conclusions: This single city survey confirms the challenges found in existing literature. However, the CCAT measurement and improvements in baseline recording of ethnicity may provide the way forward for planning and commissioning culturally-competent interventions in Coventry.

5.1. Introduction

As discussed in the previous chapters (One, Two and Three), diabetes prevalence nationally and locally in Coventry is increasing rapidly (Barker, 2006; DUK, 2010), with prevalence particularly high among ethnic minority groups (EMGs). The evidence from these previous chapters suggests inadequate healthcare quality for EMGs, primarily due to cultural elements associated with healthcare provision and insufficient cultural competences amongst National Health Service (NHS) staff (Hawthorne *et al.*, 1993; Brown *et al.*, 2006; Zeh, 2010).

The literature in Chapter One demonstrated that Coventry is a typical medium-to-large UK city with relative affluence alongside pockets of severe deprivation and health inequalities. One in 10 people are of either African-Caribbean or South Asian origins, and live in socially deprived areas with high illiteracy levels. Poor literacy is known to impede access to diabetes care (Bellary & Barnett, 2007), resulting in poor levels of disease self-management, outpatient/education attendance, glucose control and low medication concordance (Johnson *et al.*, 2000; Oldroyd *et al.*, 2005).

According to the Quality and Outcomes Framework [QOF], April 2011 data, Coventry has 66 General Practices, of which 13 are single-handed General Practices (run by one GP), providing health care to over 360,000 registered people, of whom 15,670 (4.4%) have been diagnosed with diabetes. People of African-Caribbean and South Asian origins living in Coventry are up to three and six times respectively more likely than white British to develop type 2 diabetes and are also affected by diabetes at a younger age (Barker, 2006; Grainger, 2010). Furthermore, 14% of the population with significant health inequalities are of African-Caribbean and South Asian origins. According to the Coventry Public Health Annual Report (Grainger, 2010), general practices report a lower than expected

prevalence of diabetes and hypertension due to under-screening. The Coventry's endocrine diseases and diabetes management expenditure is much lower than comparators, ranking in the bottom 10% nationally, attributed to ineffective systems and care pathways. In addition, there are no accurate diabetes data flows to measure achievement against the NICE clinical guideline 66 (NICE, 2008).

A pilot survey involving four Coventry inner-city general practices, carried out in 2009, highlighted the need for practices to record patient ethnicity to support planning and commissioning of culturally-competent diabetes interventions to enhance diabetes self-management, which is often neglected in minority groups (Zeh, 2010). Furthermore, two systematic reviews, presented in Chapters Two and Three, have demonstrated cultural barriers to diabetes service uptake across international multi-ethnic populations and effective interventions to reduce the cultural barriers. Culturally-competent interventions for improving access to health care and diabetes outcomes should be structured, including elements of culture, language, religion, and health literacy skills as well as tailored to the individual ethnic minority populations (Zeh *et al.*, 2012).

The aim of this study was therefore to investigate diabetes primary care service provision to EMGs and commissioning of such services in a typical ethnically mixed medium-sized UK city. This aim was further informed by the objectives to:

- 1) map the published evidence to a real city population and its health care provision,
- 2) explore general practices' knowledge about the ethnicity of their diabetes patients,
- 3) understand provisions implemented by general practices to meet ethnic minority population needs and their knowledge about locally available diabetes services,
- 4) explore the cultural competence of services provided and the barriers impeding provision,

- 5) examine general practice staffing by ethnicity and linguistic competences,
- 6) identify how general practice staff acquire diabetes knowledge, and
- 7) propose recommendations for other cities.

5.2. Research design and methods

This is a quantitative study using evidence derived from two systematic reviews (reported in Chapters Two and Three, in addition to the pilot General Practice survey) to design a semi structured survey.

5.2.1. Survey design

A cross-sectional population survey method, including a structured survey comprising mostly closed questions with some free text areas (see Table 5.1) was used. The survey design was informed by our systematic reviews (Chapters Two and Three), questionnaire design methods from different sources (Bowling, 2009; LoBiondo-Wood & Haber, 2009), and a 25 questions pilot General Practice Survey (Zeh, 2010). The pilot study tested the feasibility and applicability of questions and methods. This survey addressed the above objectives using five major themes: patient statistics, staffing statistics, staff training and knowledge of diabetes, culturally-competent diabetes services, cultural barriers and potential solutions (see Table 5.1).

The Warwick Diabetes Research and Education User Group was consulted and feedback was given regarding the question content. This is a group of lay people with diabetes who have an active interest in the diabetes control and care of people living with diabetes. The group meets quarterly for two hours with the main aim of advising Warwick Medical School on all aspects of diabetes research and education. Ethical approval was granted by

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National Research Ethics Service (NRES) Committee West Midlands – Solihull along with the other primary study (Chapter Six) on 16 August 2011 (Appendix 6).

Table 5:1: The General Practice Survey on ethnic minority groups with diabetes

<p>In order to maintain high standards of treatment and to ensure best possible care for our patients, I would be very grateful if you could assist me with the above study which is part of my PhD course with Warwick Medical School. I would like you to kindly spend 25 minutes of your valuable time to complete this questionnaire. Please answer all questions as fully as possible. A sum of £40 or £25 will be paid for every completed questionnaire received within 4 weeks or 8 weeks respectively from the date on the letter!</p>	
<u>Patient statistics</u>	
1) How many patients does your practice have?	
2) How many of these patients have diabetes?	
3) Does your practice have a register for recording all patients with diabetes?	Yes [] No [] Not sure []
4) Does your practice record ethnicity on its database or patient's health record?	Yes [] No [] Not sure []
5) How many patients has your practice got with diabetes who are from EMGs?	
6) How many of these patients from EMGs have Type 1 or Type 2 diabetes or gestational diabetes?	Type 1:----- Type 2:----- Gestational:-----
7) How many of these EMGs patients with Type 2 diabetes are	a) Indians:----- b) Pakistanis:----- c) Bangladeshis:----- d) African Caribbean:-----
8) How does your practice feed the number of EMGs with diabetes into this central local register, if any?
<u>Staffing statistics</u>	
9) What is the composition of your practice workforce (both full time and part time – head count)?	GPs:-----Practice nurses:----- Practice Manager:----- Receptionists:----- Others:-----Total:-----
10) How many of these staff members are full time (WTE)?	
11) How many of these staff members are from EMGs?	
12) How many of your practice staff speak South Asian languages (i.e. Punjabi, Urdhu, Hindi, Bengali, Gujarati)?	Punjabi..... Bengali..... Urdhu..... Gujarati..... Hindi..... Specify other.....

13) Does your practice have a designated Asian multilingual link worker?	Yes [] No []
14a) Does your practice have designated translators / interpreters for patients with language barriers?	Yes [] No []
14b) How often is this service in (14a) available on site?	Daily [] Weekly [] Fortnightly [] Monthly [] Quarterly [] When there is a need [] No applicable []
14c) How does your practice assess this requirement of translators or interpreters?	(i) When the patient newly registers with the practice [] (ii) When the patient books for an appointment with the practice [] (iii) When the patient arrives for practice appointment [] (iv) When patient request this service [] Not applicable []
15) Is there a lead nurse for diabetes in your practice?	Yes [] No []
16) What qualifications does the lead nurse hold for leading on diabetes?	
17) What language(s) does the lead nurse for diabetes speak excluding English?	
<u>Staff training and knowledge of diabetes</u>	
18) How does the lead nurse for diabetes receive up-to-date information on diabetes care?	
19a) How do the rest of your practice nurses, (if applicable), update their knowledge in diabetes care?	19a)
19b) Who provides these updates for the practice nurses?	19b)
20) How do your GP (s) keep up-to-date with their knowledge on diabetes?	
21) Who provides updates in diabetes care for the GPs?	
22) Has your practice got a set protocol for diabetes care?	Yes [] No [] No sure []

23) Do you know of any local resources for EMGs with diabetes?	Yes [] No []
24) Does your practice offer any educational resources for EMGs with diabetes?	Yes [] No []
25) Where does your practice refer people with diabetes for local services that it does not offer?	Other local General Practices [] Other community services [] Hospital services [] Others (please specify):
26) What services do you wish were available to support you and your practice to deliver better services to EMGs with diabetes?	----- ----- ----- ----- -----
<u>Culturally-competent diabetes services</u>	
27) What culturally-competent diabetes services are available for ethnic minority patients with diabetes at your practice? i.e.	Tick all those that are applicable
Patient Group education sessions	Yes [] No []
1-1 GP to Patient education sessions	Yes [] No []
1-1 Nurse - Patient education sessions	Yes [] No []
Multilingual link worker	Yes [] No []
Translators / interpreters	Yes [] No []
Same sex consultations with patients who prefer this option	Yes [] No []
Insulin conversion	Yes [] No []
Please list any other service (s), if applicable If your practice does not have any EMGs with diabetes, please state here	(a)..... (b)..... (c)..... (d).....
28) If you said NO to any of the above services in Number 27, what would need to happen for this to be possible? i.e. Training, funding, support. Please state and also state if the resources are available	Training [] Is the resource available? Yes [] No [] N/A [] Funding [] Is the funding available? Yes [] No [] N/A [] Additional staff [] Do you have the funding for the post? Yes [] No [] N/A [] Other [] (Please specify):
<u>Cultural barriers and potential solutions</u>	

29) List 3 cultural issues GPs or practice nurses or other staff within your practice face day-to-day when providing diabetes care to people from EMGs	1. 2. 3.	
30) Do you feel your staff have an understanding of the different cultural beliefs surrounding diabetes?	Yes [] No [] Not sure []	
31) Do you perceive that a greater cultural awareness would enhance your staff relationship with their ethnic minority patients?	Yes [] No [] Not sure []	
32) Would you consider running any educational services for EMGs with diabetes to ease cultural barriers as a practice based only?	Yes []	No []
33) Would you consider running any services for diabetes to ease cultural barriers as a locality based service?	Yes []	No []
34) What is the Do Not Attend (DNA) rate of EMGs with diabetes in keeping diabetes annual checks?	Less than 25% [] 25% - 50% []	51% - 75% [] 76% - 100% []
35) What is the DNA rate for majority white population with diabetes in keeping diabetes annual checks?	Less than 25% [] 25% - 50% []	50% - 75% [] 76% - 100% []

To ensure that your General Practice is paid for completing this questionnaire, please insert your practice's name and code.

Name: ----- Code: -----

Thank you for taking time to complete this questionnaire

Please return the questionnaire in the envelope provided together with your completed invoice

5.2.2. Population and data collection

The total population of Coventry general practices (n=66) were included with access facilitated by the Director of Public Health, who provided the contact details of all the general practices including each practice's GPs and practice manager as well as the number of registered patients and diabetes prevalence within each practice. A hard copy of the survey was initially sent to each practice manager and the senior GP of each practice, followed by an electronic copy via email, three days later. Both mailings contained instructions on how to complete the survey in paper format or online using SurveyMonkey. Two postal mailings to the practice were undertaken and non-respondents had two telephone follow-ups after 4 and 8 weeks following initial mailings. During data collection, this researcher attended three monthly Protected Learning Time meetings, generally held at Allesley Hotel, Coventry opened to all primary healthcare professionals, to raise awareness of the study. A £40 incentive was offered to general practices for every completed questionnaire received within 8 weeks and £25 paid for questionnaires received between 8 and 12 weeks.

5.2.3. Data analysis

Data analysis was planned. All questionnaire data were transcribed into the SurveyMonkey database. The data were then imported into Microsoft Excel software. Coding was performed by the researcher, who also read the free text data arising from the survey several times to formulate the main emerging themes. Missing data, (such as missing ethnicity of patients with diabetes, unanswered or incomplete questions), were also noted. Due to the nature of data collected, both descriptive statistical and qualitative approaches were used for data analysis; Microsoft Excel was used for analysing quantitative data whilst thematic constant comparative method was used for the free text data. Questionnaires were included in the analysis if more than 85% (n>29) of questions

were completed by the designated practice staff or rejected if returned after the deadline of three months. The 10-item Culturally-Competent Assessment Tool (CCAT) reported in Chapter Three (Zeh *et al.*, 2012) was used to analyse the cultural competence of diabetes services within each practice. This was to understand the levels of culturally-competent diabetes care services within each general practice.

Data were initially categorised and analysed using the original five main themes in the survey design (Table 5.1). Following initial data analyses, a report was drafted and independently reviewed by the researcher's three supervisors. Discrepancies were resolved through discussion and consensus reached amongst the research team.

5.3. Results

Following detailed constant comparisons in line with the primary aim and objectives of the study, six key themes emerged, which constitute the results of this chapter. They are:

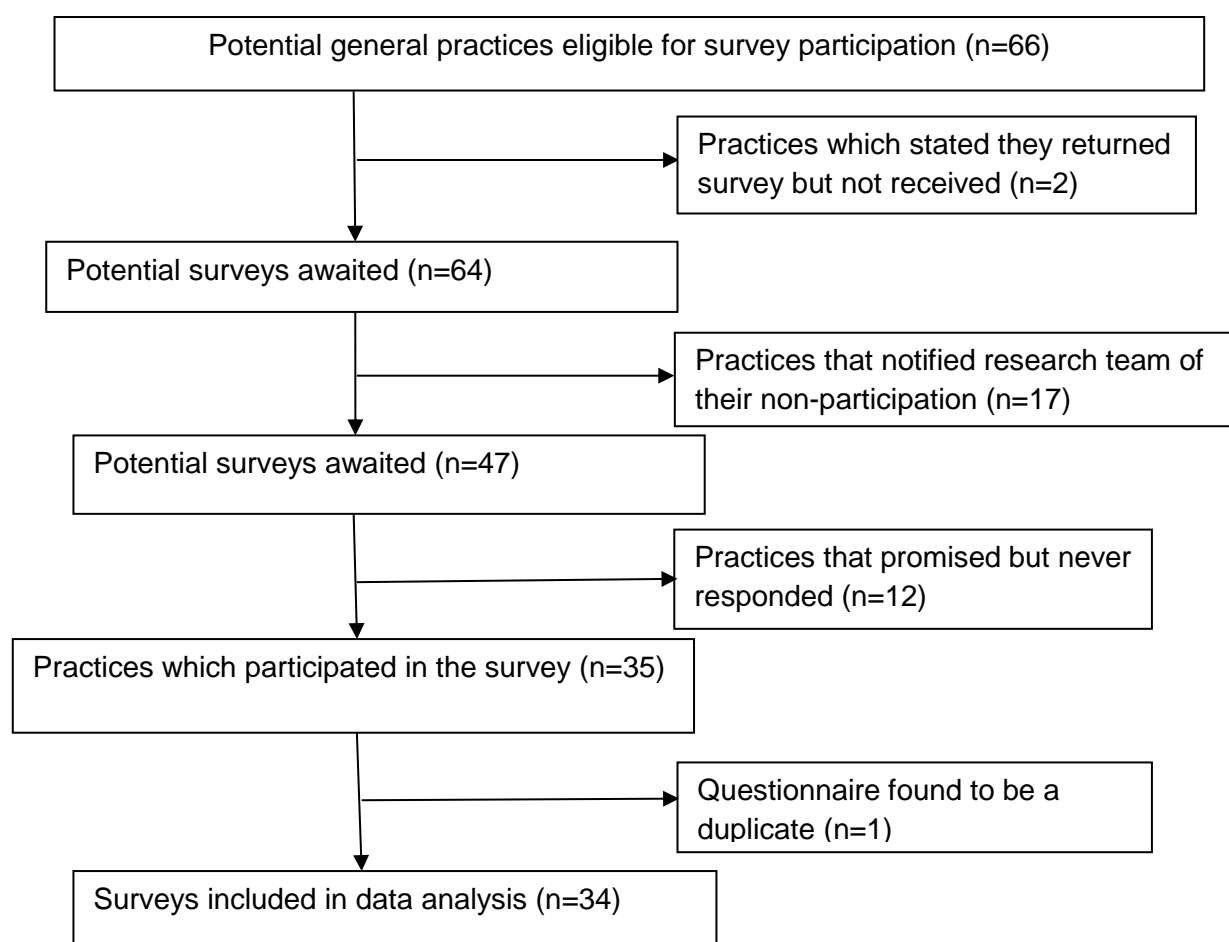
- 1) diabetes prevalence by ethnicity;
- 2) staff self-reported culturally-competent diabetes services and their knowledge about local services;
- 3) staff self-reported barriers and utilisation of diabetes annual checks;
- 4) employed ethnic minority staff;
- 5) linguistic competencies of healthcare professionals and the level of cultural competences within each general practices;
- 6) staff training and diabetes knowledge.

5.3.1. Response rate

Thirty-four (52%) general practices returned their survey; 7 online, 6 email/fax and 21 by post which are included in the analysis. The flow diagram (Figure 5.1) shows the detailed

participation of practices in the survey. Of the 34 practices, 11 returned their questionnaires on first mailing, 13 following one reminder, and 10 after two or more follow-ups. Of the 32 practices that did not return their survey, 17 contacted the researcher in writing or by phone with reasons for non-completion. The majority stated low staffing level/staff illness and related practice pressures. One participating practice refused the incentive payment stating that 'the survey was an eye-opener to review their internal practice.' A 'thank you letter' was sent to all the practices for their time and participation in the survey.

Figure 5.1: Flow chart showing the participation of general practices in the survey



5.3.2. Characteristics of participating general practices

Figure 5.2 shows the characteristics of the practices. Four participating practices did not know the number of EMGs with diabetes and consequently reported fewer culturally-competent diabetes care services ($n < 3$). Fewer practices implemented the use of a multilingual linker worker (6%). One (P4) of the six single-handed general practices had a patient population of less than 1,000, two (P15, P29) had less than 1,500, two (P8, P23) with less than 2,000, and one (P33) had 2500 patients. Figure 5.2 is further reflected within other subheadings below.

The overall patient-to-staff ratio was 405:1, with patient-to-GP ratio of 1,494:1. The patient-to-total staff ratio per practice and patient-to-GP ratio per practice are shown in Figure 5.3. The practice with the best staff-patient ratio was P9 (133:1) and the worst was P32 (619:1). Regarding patients-to-GP ratios, the lowest ratio of 576:1 was also observed in P9 and the highest was seen in P30 (2600:1).

Figure 5.2: Summary of the characteristics of participating general practices

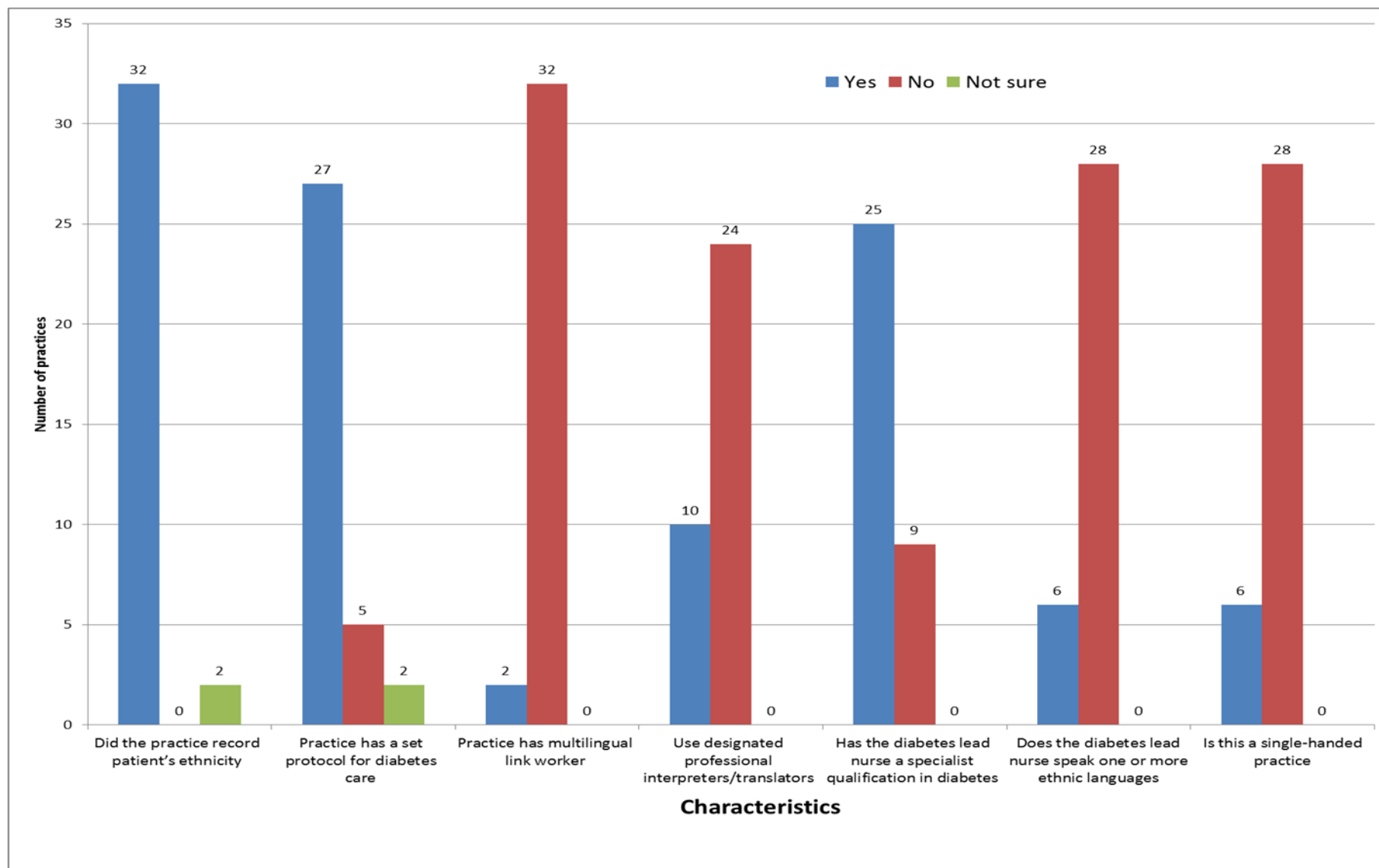
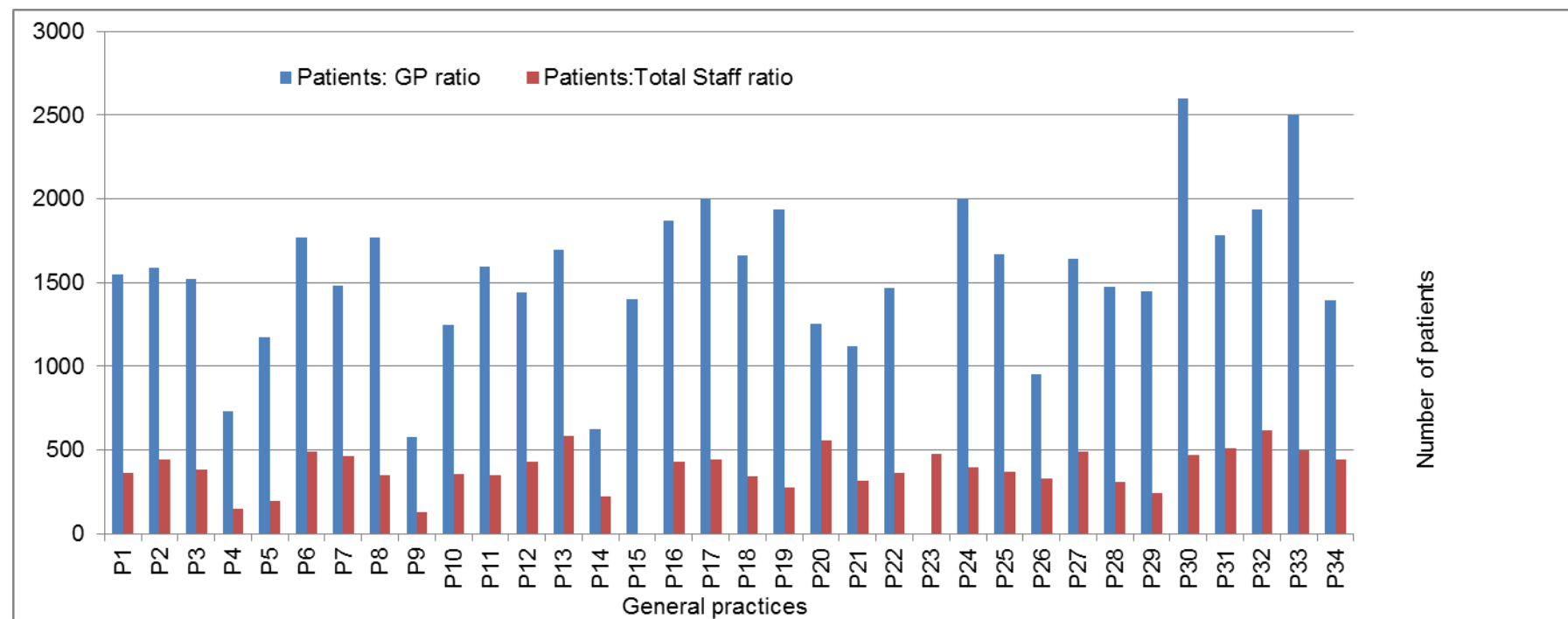


Figure 5.3: Patients-to-GP and patients-to-total staff ratios in participating general practices



5.3.3. Diabetes prevalence by ethnicity

Participating practices represented 209,149 (57.8%) of the total registered patients (361,893) in all 66 general practices in Coventry and 8,789 (4.20%) had diabetes. 2551 patients with diabetes (29%) were ethnic minorities; of which 163 (6.4%) had type 1 diabetes, 2069 (81.1%) type 2, forty-five (1.8%) lived with gestational diabetes. The distribution of 274 (10.8%) ethnic minorities with diabetes in one practice (P18) was unknown. Diabetes prevalence overall in the participating practices varied from 0.24% (P6) to 10% (P10). It ranged from 0.5% [1 out of 200] (P14) to 95.5% [525 out of 550] (P31) for patients from the minority populations. No practice stated that it did not have an ethnic minority patient with diabetes. Thirty-two out of the 34 practices (94%) reported recording the ethnicity of their populations in broad categories, of which 30 (88%) stated the number of ethnic minorities with diabetes, and 27 (84%) the distribution of those with type 2 diabetes as follows: Indians (n=1043), Pakistanis (n=405), Bangladeshis (n=120) and African Caribbean (n=264). Nine practices out of 30 (30%) [P8, P9, P10, P17, P18, P23, P24, P29, P31] [Figure 5.4] reported having more than 50% of their patients with diabetes as ethnic minorities; the highest was 96% amongst the diabetes population. Two practices (P16, P20) did not specify patient ethnic distribution, another two (P14, P30), stated having no South Asian patients with diabetes, and 6 practices had between 3-33 (3.5%-38.1%) patients of South Asian origin with diabetes.

The average number (statistical median spread) of ethnic minority patients with diabetes in the 34 practices was 43.5, which was smaller than of the majority white British population of 165.5 (see Table 5.2). Based on the standard deviation (how much variation or dispersion or spread from the average) [Table 5.2], the number of EMGs with diabetes was smaller (115.64) than the majority white British (159.19), indicating higher variability or

spread in the white British population than the EMGs. Furthermore, the diabetes ratio was 3:1; that is, for every 3 people with diabetes living in Coventry, one was from an ethnic minority origin (see Table 5.3). This calculation is based on the 30 general practices, which reported the number of different ethnic minority patients with diabetes.

The relevance of the data in Tables 5.2 and 5.3 is presented in Section 5.4 (Discussion) below.

Figure 5.4: Comparison of the prevalence of diabetes in non EMGs and EMGs

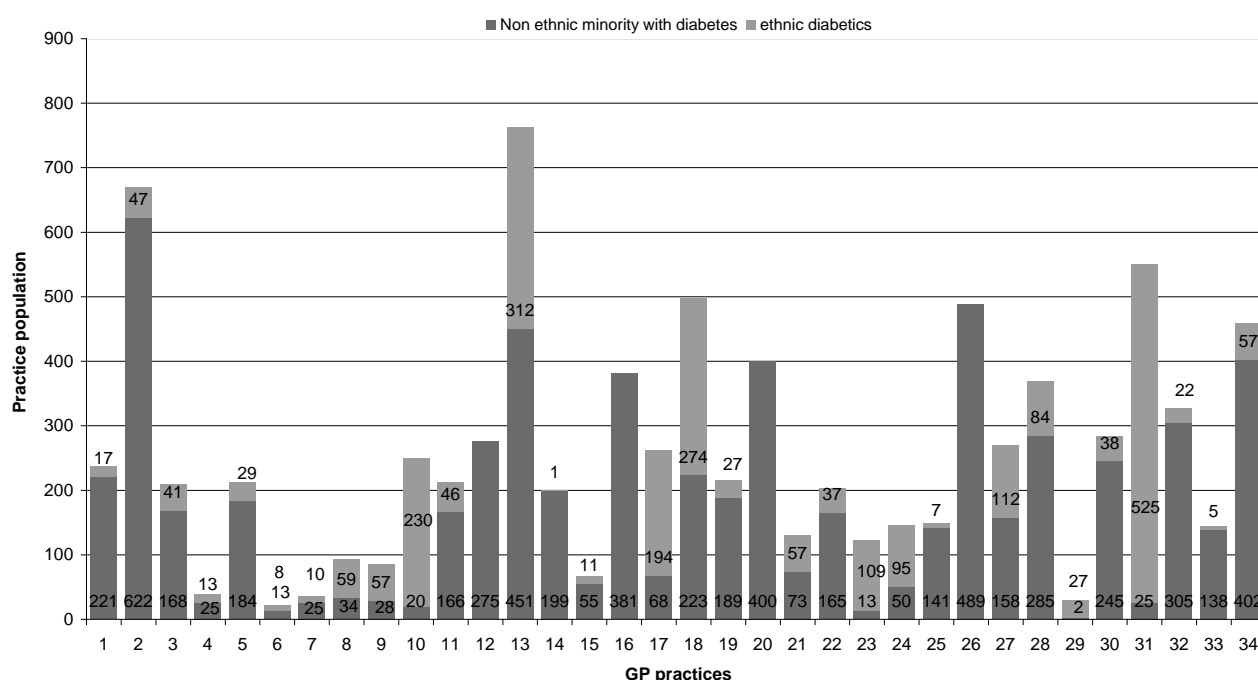


Table 5.2: Spread of patients in general practices

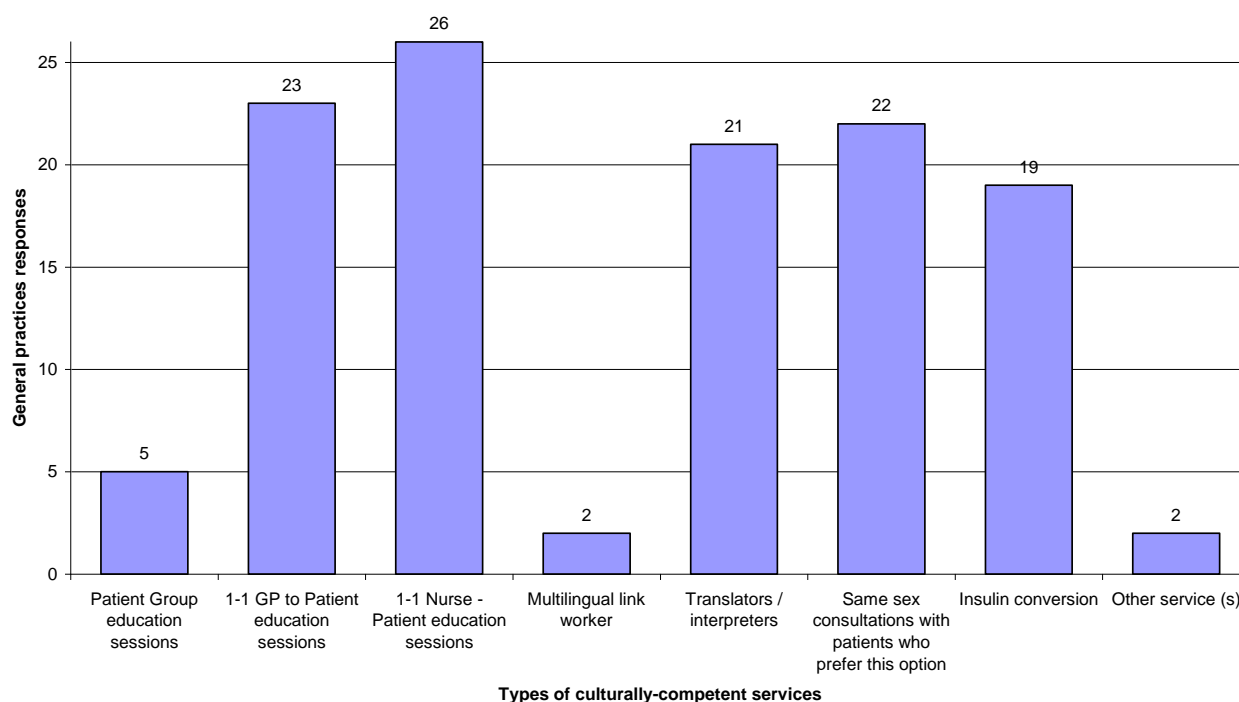
Population	Number	Mean	Median	Standard deviation
Total number of patients	209,149	6151.44	4,486	4,500.81
EMGs with DM	2,551	85.03	43.50	115.64
Non EMGs DM	6,238	183.47	165.50	159.19
EMGs with T1DM	163	5.62	2	8.62
EMGs with T2DM	2069	71.34	38	101.05
EMGs with GD	45	1.50	0	4.18
Indians with T2DM	1,043	38.63	15	67.36
Pakistanis with T2DM	405	15.58	2	34.27
Bangladeshis with T2DM	120	4.80	0	11.67
African Caribbean with T2DM	264	9.78	4	12.49

Table 5.3: Distribution comparison of different patients with diabetes

Population	Comparative	Ratio
Coventry population	People with diabetes	23:1
Patients from the studied 34 practices	Patients with DM from the 34 practices	24:1
Studied population in 30 practices with DM	Studied EMGs with DM in the 30 practices	3:1
Studied population in 30 practices with DM	Studied EMGs with T1DM	44:1
Studied population in 30 practices with DM	Studied EMGs with T2DM	4:1
Studied population in 30 practices with DM	Studied EMGs with GD	161:1
Studied population in 30 practices with DM	Studied Indians with T2DM	7:1
Studied population in 30 practices with DM	Studied Pakistanis with T2DM	18:1
Studied population in 30 practices with DM	Studied Bangladeshis with T2DM	60:1
Studied population in 30 practices with DM	Studied South Asians with T2DM	5:1
Studied population in 30 practices with DM	Studied African Caribbean with T2DM	27:1

5.3.4. Staff self-reported culturally-competent diabetes services and their knowledge about local services to ethnic minority groups

Self-reporting varied widely, with all 34 practices reporting eight culturally-competent diabetes care services in appropriate language (Figure 5.5). The delivery per practice of at least three of these services was reported by 25 practices. Only one practice (P30) reported not delivering culturally-competent diabetes services, while three (P11, P12, P31) provided one and five (P7, P8, P25, P26, P33) provided two. One-to-one nurse-to-patient diabetes care services in an appropriate language was delivered by most practices (n=26) and a multilingual South Asian link worker model was the least provided by two practices (P10, P13). Five practices (P4, P10, P15, P23, P24) reported offering informal patient group education sessions. Two practices reported offering additional services in an appropriate language: dietary advice (P4) and retinal photography (P20).

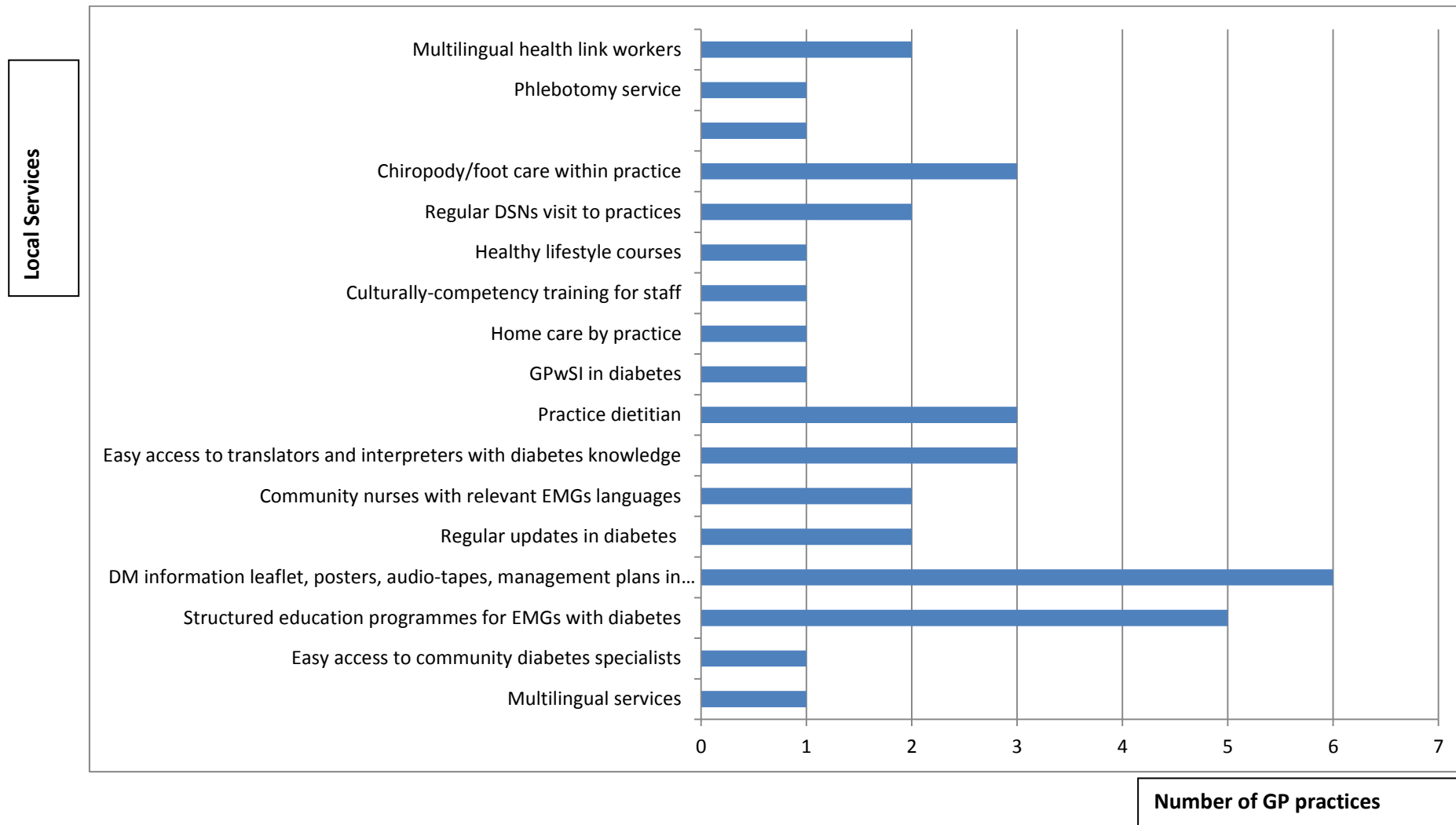
Figure 5.5: Staff self-reported culturally-competent diabetes services provided to EMGs

Practice staff had knowledge of locally available services not offered within their practices. Fifteen (43%) practices were referring their patients with diabetes to both community and hospital services, for services they did not offer; fourteen (41%) were referring to community services only, two (6%) were using hospital services only, and six (18%) were using other voluntary and community sector services. Two of the six practices that were referring to other community services were not using hospital and community services.

Twenty-one practices (62%) identified local services they perceived would be beneficial in supporting them to deliver better care services to ethnic minorities with diabetes within their practices, with the majority stating structured culturally-competent education programmes (n=5) and multilingual information in various formats (n=6) [see Figure 5.6].

Furthermore, twenty-one (62%) practices were unaware of the Coventry central register for diabetes. To enhance culturally-competent diabetes services specifically for minority groups in an appropriate language, 32% (n=11) practices stated they would consider running practice and locality-based services and 38% (n=13) reported that they would not consider running either. Fifty percent (n=17) stated that they would only consider practice-based diabetes services and 50% (n=17) stated a requirement for locality-based services only.

Figure 5.6: Local services stated by staff perceived would support practices to deliver better services to EMGs with diabetes



5.3.5. Staff self-reported barriers and utilisation of diabetes annual checks

Cultural and organisational barriers were identified as contributory factors to inappropriate diabetes care services. All except five practices (P12, P28, P30, P32, P33) reported at least one cultural barrier (Table 5.4) experienced by their staff in their day-to-day interaction with ethnic minority people with diabetes. Of the remaining 29 of the 34 practices, 6 reported two barriers and 21 stated the maximum requested three cultural barriers experienced with minority patients by their staff. Cultural diversity in relation to linguistic differences between service providers and ethnic minority patients (n=15) and a lack of understanding by health care professionals about the strong traditions around ethnic food (n=19) were most commonly reported as barriers to culturally-competent service delivery.

Table 5.4: Staff self-reported barriers impeding delivering of effective diabetes services to EMGs

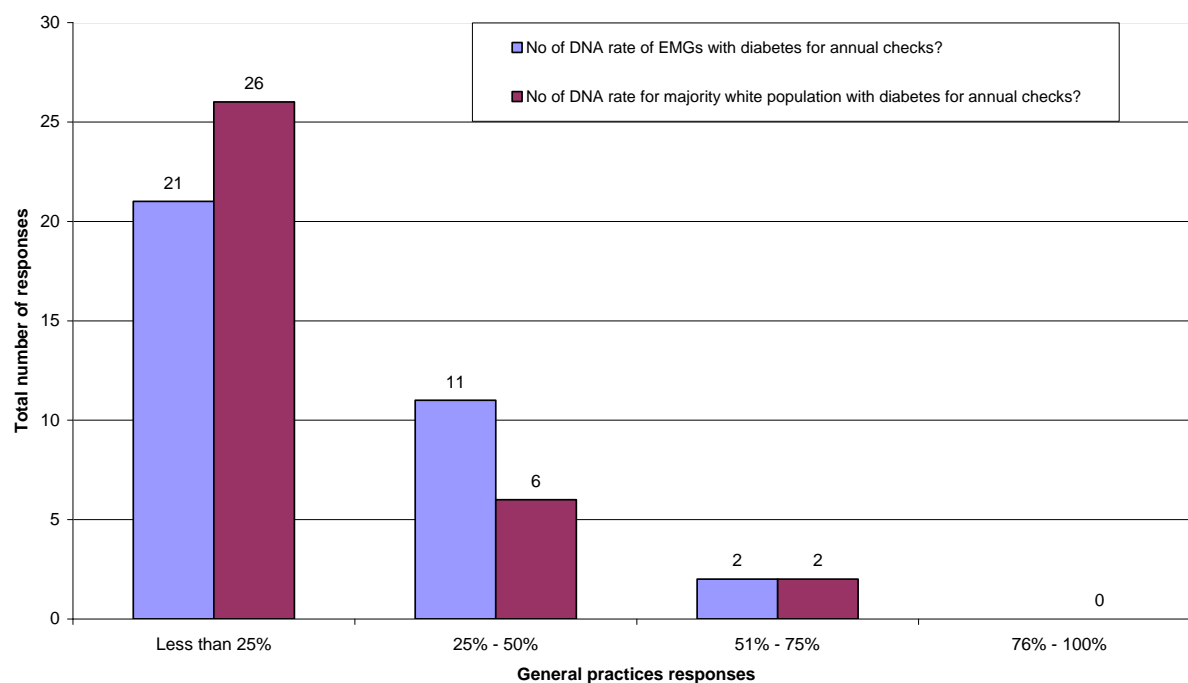
Language barrier (n=15)	Cultural differences (n=10)	Low health literacy (n=1)
Strong traditions relating to food (n=19)	Low concordance/compliance issues with medication due to stereotypes around western medicines (n=6)	Missed communication amongst patients and staff due to cultural differences (n=2)
Religious beliefs, e.g. refusing to take insulin on grounds that it's produced from pigs (n=4)	Low health literacy level resulting in lack of diabetes knowledge (n=4)	High DNA in EMGs (n=3)
Variation in overseas prescriptions posing non-adherence in self-medication (n=2)	Poor/low motivation in diabetes self-management due to cultural reliance on HCPs (n=1)	Like all clinical services at practice-based level (Do not want travelling to different locations) (n=1)
Self-denial of diabetes based on cultural norms (n=3)	Fasting posting different meal times (n=2)	Different beliefs about physical exercise (n=4)
Curative belief of diabetes (n=1)	Gender differences (n=1)	Patients' social and financial circumstances (n=1)

Organisational barriers included lack of funding, inadequate cultural competence training and low staffing levels. Some practices stated that they would need additional funding (n=21), training (n=23) and staff (n=21) to implement better culturally-competent diabetes

services. Two practices, which had single figure (P14) and five (P33) ethnic minority patients with diabetes respectively stated there was no need for specific services for these patients within their practice as they were neither viable nor cost-effective, while one practice (P1) stated the lack of time and space for non-implementation of such services.

Four out of the six single-handed general practices were unaware of locally available resources for ethnic minority patients with diabetes. Twenty-one (61%) out of the 34 participating practices reported adequate staff understanding of the different patients' cultural beliefs surrounding diabetes care services, 5 (15%) reported inadequate understanding and 8 (24%) were unsure. Better cultural awareness was perceived to improve practice staff's relationship with ethnic minority patients in 16 practices (47%), with 35% (n=12) being unsure, and 18% (n=6) out of the 34 participating practices stated that better cultural awareness would not make any difference.

The number of patients that 'did-not-attend (DNA)' for their diabetes annual checks was better in the practices with majority white British compared to the EMGs; 26 practices reported less than 25% DNA rates in the majority white British populations compared with 21 in EMGs, between 25%-50% DNA rates were reported by 6 practices in the white British compared with 11 in EMGs [Figure 5.7]. DNA rates above 50% were the same in both the white British and minority populations (Figure 5.7).

Figure 5.7: Comparison of DNA rates in diabetes annual checks in majority and minority groups

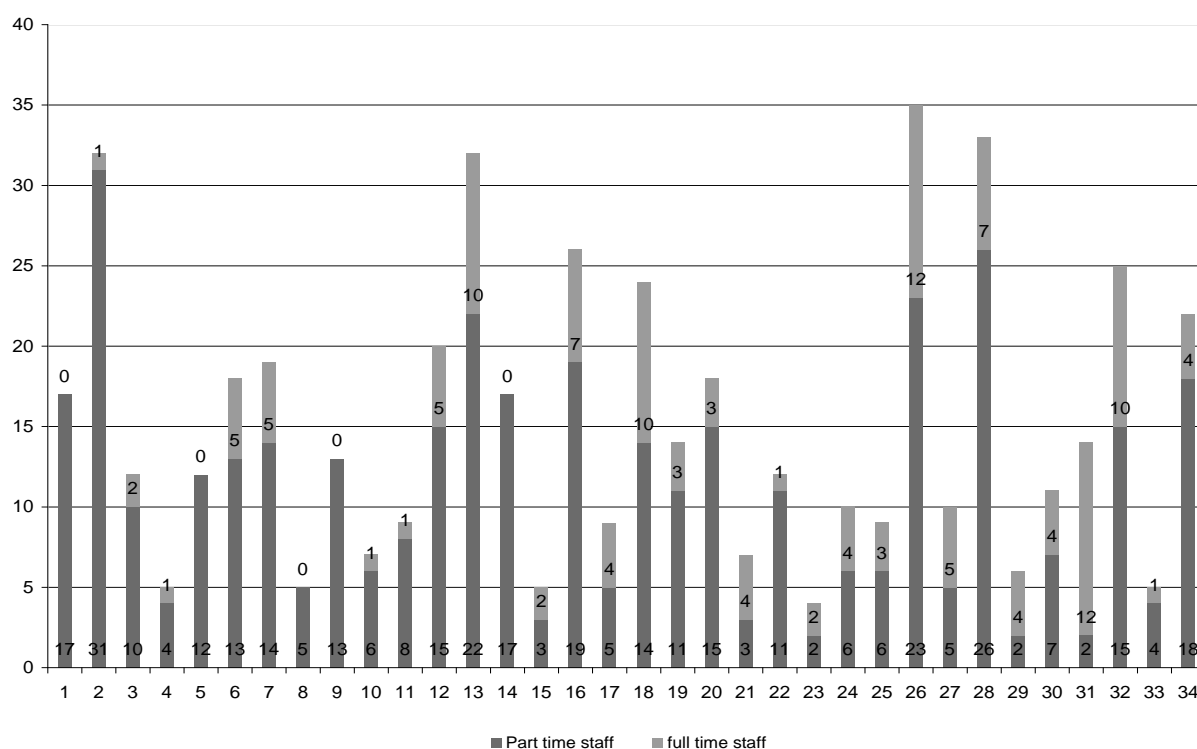
5.3.6. Employed ethnic minority staff

This theme presents staffing by ethnicity, linguistic competences of practice staff and the level of cultural competences within each general practice.

The 34 participated general practices reported having a total of 517 staff of which 109 (21.08%) were from EMGs and 133 (25.73%) were full time employees. Table 5.5 details the staffing statistics and the spread of the staffing within the general practices. The standard deviation of full-time staff (3.51) was smaller than part-time staff (7.44), showing less variability or spread of the estimate from the data. The staff distribution per practice (full time and part time) as reported by practices is illustrated in Figure 5.8.

Table 5.5: The spread of staffing in general practices

Staffing	Number	Mean	Median	Standard deviation
Total number of staff	517	15.21	12.50	8.97
Full time	133	3.91	3.50	3.51
Part time	384	11.29	11	7.44
GPs	140	4.12	3	3.01
Practice nurses	77	2.26	2	1.36
Practice managers	33	0.97	1	0.17
Receptionists	183	5.38	5	3.07
Other staff group	94	2.76	2	3.04
Staff from EMGs	109	3.21	2	3.43

Figure 5.8: Full time and part time staff per general practice

Participating general practices reported that of the 517 staff, 164 (24%) could speak one or more ethnic minority language(s). Five south Asian languages: Punjabi, Hindi, Urdu, Gujarati and Bengali were identified as frequently spoken in Coventry with Punjabi being the most spoken language and Bengali the least, in 24 of the participating general practices. The remaining 10 practices stated all their staff spoke English only. In Coventry

primary care, the data show that Punjabi is spoken by 44 staff, Urdu by 30, Hindi by 36, Bengali by 5 and Gujarati by 19.

Only one practice (P27) had staff who spoke all five South Asian languages between them. Despite diabetes care being provided mostly by practice nurses, only six (19%) [P2, P8, P10, P23, P28, P31] of the 31 practice lead nurses for diabetes, spoke one or more South Asian/ethnic minority languages as follows; Punjabi - 6, Hindi - 5, Urdu - 1, Gujarati – 3. No one spoke Bengali. Eight practices (P9, P13, P17, P18, P21, P24, P27, P29) had an ethnic minority population of greater than 40% (27-312) with diabetes, yet had no lead nurse who spoke any of the ethnic minority languages. However, within these eight practices, at least one staff spoke at least one of the relevant minority languages. One of the eight practices (P21) with 44% (n=57) ethnic minority patients with diabetes stated language barrier as a major issue but did not use any form of interpreters/translators or multilingual link worker. Another (P13), with 41% (n=312), implemented the use of both interpretation/translation and link worker models. One of these practices (P18) with a 55 % (n=274) prevalence of diabetes in its registered ethnic minority population, did not use any of these two services because it had 4 ethnic minority staff who spoke 5 different ethnic languages between them (and used informal interpreters when necessary) to meet the language differences of their patients. The rest of the five practices used either informal interpreters/translators or multilingual link worker. Professional translation/interpretation service was provided by 16 practices when an ethnic minority patient requested the service and the requirement for this service was often determined as per the individual patient's needs in 19 practices.

Assessment of the level of cultural competences of diabetes services within each of the 34 participated general practices using CCAT (see Table 5.6) found 56% (n=19) of practices

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to be delivering highly culturally-competent diabetes care services (scoring 90%-100%), 26% (n=9) were moderate, scoring 70%-89%. The remaining 18% (n=6) delivered a lower number of culturally competent diabetes services (<70%).

Table 5.6: Assessment of culturally-competence level of general practices using the tool proposed by Zeh et al. (2012)

Practices	1	2	3	4	5	6	7	8	9	10	%
P1	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P2	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90%(A)
P3	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P4	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	85%(B)
P5	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P6	Yes	No	Yes	Yes	Yes	No	Yes	No	Unclear	Yes	60% (C)
P7	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P8	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P9	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P10	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P11	Yes	No	Yes	Yes	Yes	Unclear	Yes	Unclear	Unclear	Yes	60% (C)
P12	Unclear	Yes	Unclear	Unclear	Yes	Yes	Yes	Unclear	Unclear	Yes	50% (C)
P13	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P14	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P15	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P16	Unclear	Unclear	Unclear	Unclear	Yes	Unclear	Yes	Unclear	Unclear	Yes	30% (C)
P17	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P18	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P19	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	70% (B)
P20	Unclear	Yes	Unclear	No	Yes	Yes	Yes	Yes	Unclear	Yes	55% (C)
P21	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	70% (B)
P22	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P23	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P24	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	70% (B)
P25	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Unclear	Yes	70% (B)
P26	Unclear	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	60% (C)
P27	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P28	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P29	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P30	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	80% (B)
P31	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	80% (B)
P32	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	90% (A)
P33	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	80% (B)
P34	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	80% (B)

Culturally-Competent Assessment Tool for Healthcare Interventions in Ethnic Minority Groups by Zeh et al. (2012)

Assessment Factors for Culturally-Competent level of each practice	
1	Does the intervention have a clear focus on ethnic minority groups?
2	Is the intervention sensitive to the specific linguistic needs of the participants?
3	Do the service providers demonstrate cultural awareness?
4	Do the service providers have cultural knowledge?
5	Do the service providers have specialist knowledge in the clinical condition?
6	Are the linguistic needs of patients or clients met by (a) health workers speaking the patient's/client's main language (b) Health workers speaking the patient's/client's second language? (c) interpreters? (d) translators? (e) Audio–visual recorded aids?
7	Are the health literacy needs of patients and/or clients met by the delivery health workers or expert patients?
8	Are the service providers culturally-competent in delivering the intervention?
9	Are the service providers culturally sensitive?
10	Does the intervention work?

Note: For an intervention to be culturally-competent, the answer is 'yes' to number 1 & 2 and at least 6 other questions in 3-10 scoring above (70%)

Scoring classification of the quality of the culturally-competent intervention

- Highly culturally-competent must answer 'yes' to 90%-100% of the assessment factors or criteria and scored as 'A'
- Moderately culturally-competent intervention must answer 'yes' to at least 70%-89% (B)
- Low culturally-competent intervention scores less than 70% (C)

5.3.7. Staff training and diabetes knowledge

All 34 (100%) practices stated that both their medical and nursing staff generally receive regular formal training on diabetes care. Both GPs and practice nurses receive up-to-date diabetes knowledge from diverse sources: in-house training, attending clinical meetings and formal courses locally/nationally during study days and protected learning time (PLT), e-learning, reading relevant clinical journals and websites. This training/knowledge was provided to them by Coventry PCT/Postgraduate Medical Education (PGME)/GP consortia, lead practice nurse for diabetes, diabetes specialist nurses, GPs with a special interest (GPwSIs) in diabetes, hospital consultants, academic specialists (from Warwick Medical School, Coventry University and other academic institutions), peer support, other professional healthcare groups such as pharmaceutical companies and Diabetes UK.

Of the thirty-one (91.18%) general practices with a lead nurse for diabetes, twenty-five (80.65%) of these lead nurses had undertaken formal training leading to a specialist qualification in diabetes and continued to maintain their professional knowledge via various updates in diabetes. Of these 25, fifteen of them had diabetes specialist qualifications at certificate level, diploma (n=9), and masters level (n=1). The majority of them had obtained their qualification locally from the University of Warwick (n=13). All the six single-handed general practices reported having a lead nurse for diabetes of whom four (66.66%) had a formal specialist qualification in diabetes.

5.4. Discussion

5.4.1. Discussion of the principal findings

This single city survey has investigated diabetes primary care service provision to EMGs and commissioning of such services in a typical ethnically mixed medium-sized Coventry

city by mapping the published evidence to a real city population and its health care provision. Furthermore, it has addressed the research aim and objectives by exploring general practices' knowledge about the ethnicity of their diabetes patients, understanding provisions implemented by general practices and their knowledge about locally available diabetes services, exploring the cultural competence of services provided and the barriers impeding provision, examining general practice staffing by ethnicity, their linguistic competences and identifying how general practice staff acquire diabetes knowledge.

The findings have demonstrated the challenges of delivering tailored diabetes care services found in existing literature across international multi-ethnic populations (Hawthorne *et al.*, 1993; Brown *et al.*, 2002; Fleming & Gillibrand, 2009; Zeh *et al.*, 2012), in addition to the literature presented in Chapter Two. Although one in ten people living in Coventry is from an ethnic minority origin, the findings from this survey showed a disproportionality of those affected with diabetes, as one in three people of the diabetic population was from an ethnic minority group, implying that special attention is required to tackle this diabetes health inequality in Coventry. The absolute number of people with diabetes from EMGs was lower compared to the absolute numbers in the majority population, which is unsurprising given that only one in ten people living in Coventry is from an EMG (Barker, 2006; Grainger, 2010). However, considering the sample size of each group with diabetes, it was surprising to find a higher variability of 159.19 in the white British population compared to that of 115.64 in EMGs.

There was little detectable difference between the participating and non-participating general practices when assessed from publicly available data sources (QOF, 2011). For instance, of the 32 non-participating practices, the highest diabetes prevalence was 7.91%

(QOF, 2011) compared to 10% in one of the participating practices. Seven non-participating compared with six participating practices were singled-handed GPs. The patient population of each of the seven non-participating practices ranged from 419 to 2,966 compared with 734 to 2,500 in the participating practices. The highest patients-to-GP ratio in all the non-participating practices was 3,191:1 compared to 2,600:1 in the participating practices. The ethnicities of patients or staff were unavailable in the non-participating practices as the data were not publicly available. Therefore, the non-participation of some practices may be due to the period of conducting this survey (between November and January), which coincides with staff pressures of Christmas and preparing for QOF inspections, as the latter was cited by some general practices.

A significant number of the participating practices reported higher diabetes prevalence in the EMGs when compared to the majority British Caucasian population. Type 2 diabetes appeared to be fast growing, concurring with previous epidemiological data that has demonstrated increasing prevalence at an alarming rate in the UK (74%), in contrast to the USA (41%) (Gonzalez *et al.*, 2009), especially in EMGs who are particularly vulnerable (Baradaran & Knill Jones, 2004). Unlike the NHS Scotland document (NHS-Health-Scotland, 2004), which noted a paucity of ethnicity data in most diabetes registers (approximately 30% of General Practices and Community Centres recording ethnicity), practices in this survey numerically reported their patients' ethnicity in broad categories (94%). Such reporting is fundamental for effective commissioning of healthcare services, and should be based on patients' needs and indices of deprivation rather than patient numbers or age. As completion of this ethnicity information was high, more attention needs to be given to the accuracy of recorded information. For example, one practice in the survey reported the total number of ethnic minority people with diabetes but did not

know the ethnic distributions. A recent survey also found substantial variation between hospitals in the accuracy of ethnicity information, especially around EMGs (Saunders *et al.*, 2013).

Despite reported challenges across general practices, practice staff were aware of the need to deliver tailored services to minority patients with diabetes, with referrals made to different providers for services not offered at the patient's registered practice. Fifty-six percent of the general practices in Coventry were delivering highly culturally-competent diabetes services, but comparisons cannot be made with other comparable cities as no such measurements have been previously used (Zeh *et al.*, 2012). However, two practices (P14, P33) reported the lack of viability and cost-effectiveness of implementing specific culturally-competent diabetes services for minority patients as they had low ethnic minority patient numbers within their practices, which could indicate that these patients are disadvantaged compared to their ethnic majority counterparts (Roberts, 2007). It is important that such general practices have alternative arrangements to facilitate appropriate referrals in line with the NSF for Diabetes and NHS Constitution (DH, 2001; DH, 2010).

In spite of the high provision of culturally-competent diabetes services in Coventry, the impact on patient outcomes is unclear from the data collected. Further studies are required to assess patient outcomes as well as patient and staff satisfaction levels (Zeh, 2010). There was some indication that single-handed general practices were working in isolation as they were unaware of other locally available services to minority patients with diabetes. The majority (83%) of the single-handed practices did not know if Coventry had a central register for diabetes, suggesting that integration, sharing good practice and

benchmarking of the diabetes provision may help to improve care. Of all the EMGs reported in this study, Indians were the highest group living with diabetes in Coventry, which can be attributed to the fact that this group is the largest minority population in Coventry (Owen, 2005).

In line with previous studies (Lawton *et al.*, 2008; Fleming & Gillibrand, 2009), the survey found the most problematic areas in diabetes service provision to ethnic minorities were language barriers and cultural issues around food. However, scarcity of resources coupled with less culturally-competent providers within some practices could partly explain the reason for the variation reported in diabetes service provision as previously cited in other studies (Cone *et al.*, 2003; Mainous *et al.*, 2006; Zeh *et al.*, 2012). Although the majority of practice lead nurses for diabetes were pivotal to diabetes care delivery, only a few spoke any of the ethnic languages, and none spoke Bengali. This may perhaps explain patient under-usage of annual diabetes checks, raising questions about effectiveness of communication. Arguably, in healthcare delivery, effective communication between patients and healthcare professionals requires the latter to understand both the patient's language and the culture (Zeh, 2010). An understanding of cultural norms and health beliefs of South Asian patients with type 2 diabetes by linguistically-competent health workers has ensured effective communication, leading to better diabetes health-related outcome measures (Hill, 2006). It is imperative that education around food and dietary change be based on the kinds of foods EMGs are already accustomed to (Lawton *et al.*, 2008; Goody & Drago, 2009). Such initiatives should be negotiated, affordable and culturally sensitive, reflecting the ethnicity and social context of the individuals and in accordance with their religious beliefs to ensure concordance (Hill, 2006; Brown, 1997).

5.4.2. Strengths and limitations

This was a localised survey with a high interest factor, involving practices with EMGs who have higher prevalence of diabetes, a daunting and challenging area for effective commissioning of healthcare services in Coventry and nationally (Roberts, 2007; Zeh, 2010). A population survey method was used to give an opportunity to all general practices in Coventry to provide insight into their current diabetes services. The cash incentive payment of £40 or £25 for each completed questionnaire may have encouraged practices to return their questionnaire promptly, in addition to the researcher's attendance at three monthly Protected Learning Time meetings, generally opened to all primary healthcare professionals. Although our response rate of 52% is lower than two previous General Practice surveys of 100% and 67% respectively (McColl *et al.*, 1998; Zeh, 2010), seventeen non-responders (55%) contacted the researcher with reasons for non-participation. Furthermore, the cultural competence level of diabetes services within each responded practice was systematically assessed.

The scope of this study was limited to healthcare professionals' perspectives only, and similar surveys are warranted to concurrently investigate ethnic minority patients' views. As questionnaires were completed by practice managers or designated staff within their practices (GPs or practice nurses), some of the responses would have been based on their professional perception of diabetes services provided within their practices. The diabetes rates of each of the participating practices were verified using the Quality and Outcomes Framework (QOF) data of April 2011 and found to be very similar. However, one practice that reported having 10% diabetes rate was found to have almost doubled its figures, highlighting the difficulty with subjective self-reporting (Griffiths, 2009; Horner *et al.*, 2002; Johnson *et al.*, 2009). Our questionnaire was refined; nonetheless, gaps were

still identified in question 30, which asked '*Do you feel your staff have an understanding of the different cultural beliefs surrounding diabetes?*' In fact, two practices indicated a fourth response of 'partially' as the provided 'yes' or 'no' or 'not sure' responses did not fit into what they perceived of their staff. Future improvements could involve validating the survey in general practices in other UK and/or international cities, to investigate similar research topics. It is unclear if the staff completing the questionnaire fully understood what constituted a culturally-competent service. It would be interesting for general practices to use the CCAT (Zeh *et al.*, 2012) to assess the cultural competence of their interventions aimed at any ethnic minority healthcare population within general practices.

5.5. Conclusion and recommendations for future research

This study sought to elucidate cultural barriers to diabetes service uptake and services across general practices in Coventry. There was evidence of culturally-competent diabetes primary care service provision to minority groups across most general practices, especially one-one patient-to-nurse interactions in appropriate language. However, lack of culturally sensitive resources, strong traditions around food and language barriers between service providers and ethnic minority patients were also identified. Effective communication is fundamental to safeguarding the quality of health care, particularly in EMGs with cultural and linguistic needs, and the use of '*informal interpreters*' raises doubts about quality of information (Szczepura *et al.*, 2005). As diabetes service provision within practices appeared to be nurse-led, the inclusion in both the undergraduate and graduate nursing curricula of the eight themes identified in the systematic review on cultural barriers impeding EMGs from accessing effective diabetes services reported in Chapter Two, is recommended. These programmes could impart appropriate knowledge and skills to service providers to develop and deliver culturally-competent diabetes

services tailored to the needs of EMGs. Such training should be structured, including elements of culture, language, religion and health literacy skills of the specific minority group, which are crucial in delivering tailored culturally sensitive service (Zeh *et al.*, 2012). Where little or no linguistically and/or culturally-competent staff are available, a Diabetes Specialist Multilingual Link Worker (DSMLW) Service, is recommended to support general practices and empower patients with language and other cultural barriers to self-manage their diabetes. This DSMLW service framework is presented in Chapter Six.

Appropriately recording ethnicity provides an optimistic baseline for commissioning services, but further investigation in similar multi-ethnic cities is required. If confirmed, then this has important implications for practice and, particularly, the need to develop processes for use in other cities to audit their health care provision for similar populations. However such initiatives would require maintenance of a centralised ethnicity register by all primary care providers, perhaps with additional incentives under QOF and/or other innovative schemes for the management of diabetes. Ethnicity data of every patient should be collected once by general practices and linked through healthcare databases and verified at subsequent clinical visits (Iqbal *et al.*, 2012a). Effective ethnicity information collection and usage will demonstrate the extent of disparity in diabetes healthcare provision and could assist service planners and healthcare commissioners to develop appropriate services (Zeh, 2010).

General practices should measure the cultural competence of their interventions aimed at any ethnic minority population using CCAT, which proved successful in a previous study (Zeh *et al.*, 2012) as well as the current study. Future studies should therefore consider the views of service-users to determine if the reported levels of culturally-competent diabetes services across most of the general practices mirror our findings and its impact on their outcomes. Clinical audits are also warranted in this area.

CHAPTER SIX

DESIGNING AN EFFECTIVE CULTURALLY-COMPETENT DIABETES CARE SERVICE IN PRIMARY CARE: A PARTICIPATORY RESEARCH STUDY TO IMPLEMENT EVIDENCE

6.0. Abstract

Background/aim

Systematic reviews and General Practice survey (Chapters Two, Three and Five) have identified cultural barriers and effective interventions for improving cultural competence in diabetes healthcare. This study aimed to explore and implement some of these findings by designing an interventional framework to cater for the needs of EMGs with diabetes in Coventry.

Methods

A purposive participatory case study was conducted in one Coventry inner-city practice between April 2012 and March 2013, using weekly participant observations, monthly participatory group meetings and one post-participatory one-to-one semi-structured interview with three patients, four general practice staff and two multilingual link workers. Data were analysed using qualitative methods.

Results

The operational activities of this general practice involving staff and patients demonstrated both strongly evidence-based culturally-competent and less culturally-sensitive practices. For instance, some ethnic minority patients with cultural differences were consulted by healthcare professionals from the same ethnic backgrounds, thereby ensuring cultural and linguistic concordances. However, there were also occasions where children interpreted for their parents and where patients with language barriers consulted without the use of professional or lay interpreters. The practice prioritised the designing of a Diabetes Specialist Multilingual Link Worker model, to reduce the inequality in diabetes primary care service provision. Key elements of the model were training and education, function of the multilingual link worker, information sharing, partnership working, and service commissioning.

Conclusions

A Diabetes Specialist Multilingual Link Worker Framework to address deficits in general practice cultural competence was developed for pilot testing. The involvement of a broad group of stakeholders ensures interventions to improve EMGs' access to effective diabetes care in primary care are appropriate and feasible. This may ultimately result in greater effectiveness.

6.1. Introduction

There is a transition from doing research on participants to doing research with participants (Cornwall & Jewkes, 1995). The chapter begins with describing the research methodology and design, then moves on to address the recruitment techniques and challenges, data collection tools, and ethical issues. The work explores building effective relationships and trust with practice staff, coupled with how regular supervision team meetings and other learning sources prepared and supported the researcher to successfully use participatory research (PR) methodology.

The use of qualitative approaches during data collection and analysis are examined, and the reliability and validity of the study. Results are focused on the designing of a Diabetes Specialist Multilingual Link Worker (DSMLW) intervention framework, initiated by the joint PR collaboration from both staff and patients. These changes and the voices of patients and staff in the provision of diabetes care services to ethnic minority populations are presented. The results are ordered chronologically, based on the research methods used (participant observations, participatory research group meetings and post-participatory research interviews), and then brought together, based on consistent themes across the three research methods.

Conclusions and recommendations drawn from the study indicate the need for a pilot exploratory trial to determine the clinical, psychosocial and economic cost effectiveness of the DSMLW model.

6.2. Research aim/objectives

This study aimed to explore, prioritise and design a culturally-competent service framework to cater for the needs of EMGs with diabetes in Coventry.

The aim is underpinned by the objectives, to:

- (a) Verify the cultural barriers reported in Chapter Five, and explore how they impede effective diabetes care provision to EMGs from the perspectives of both ethnic minority patients and staff within the general practice,
- (b) Appraise evidence of cultural barriers with the research participants to identify evidence based interventions likely to make a difference in their context,
- (c) Prioritise and design a culturally-competent service framework to cater for the needs of EMGs within the general practice and propose recommendations for other general practices.

6.3. Participatory research methodology, selection and justification

PR was adapted for this study. It is a research paradigm in which the research relationship is collaborative, such that research is with, for, or by the community, and the researcher is one partner in the research process (Truman *et al.*, 2008). Participatory methodologies arises from qualitative research approaches which aim to reflect, explore and disseminate the views, concerns, feelings and experiences of research participants from their own perspectives (Swain and French, 2004). In so doing, PR introduces an egalitarian power relationship between the researcher and the research participants (Brechin, 1993), thus allowing the research to be owned and controlled by research participants as well as researchers. This distinctive feature makes PR different from other research approaches, such as action research or cross-sectional surveys (Zarb, 1992; Cornwell and Jewkes, 1995). This is because the PR approach engages '*participants in the agenda setting and*

review (Everitt *et al.*, 1992:50)' of the research in a non-hierarchical order. This view is shared by Chambers (1986) who argues PR as a new research paradigm is gaining ground particularly in the developing countries, where 'a coherent and mutually supportive pattern of concepts, values, methods and action amenable to wide application' is displayed.

PR methodology was appropriate for this research. It united diverse stakeholders, from different cultural backgrounds, to explore, prioritise, select and initiate the designing of a culturally-competent diabetes service framework to assist the general practice to provide better diabetes care services to their ethnic minority patients with diabetes. The researcher entered the research setting without knowing the culturally-competent diabetes service which the general practice staff would decide to prioritise, and design. This approach is different from, for example, participatory action research (PAR), which is a recognised form of experimental research that focuses on the effects of the researcher's direct actions of practice within a participatory community, with the goal of improving the performance quality of the community or an area of concern (McNiff & Whitehead, 2006). In PR, in order to bring about improvements in a specific context, those within a given context investigate aspects of their own practice whilst thinking through and taking into account the experiences and perceptions of the different stakeholders (Ainscow *et al.*, 2006), which worked well in our PR meetings.

PR encourages participants to see themselves as researchers, that is, the research is with rather than on people (Reason and Heron, 1986). This research methodology has been successfully applied in similar studies (Cancian, 1993; French and Swain, 2004; Horn *et al.*, 2008; Johnson *et al.*, 2009) because the views of the research participants could best

be elicited if power is shared evenly. PR was designed to yield fruitful outcomes as the participants would have explored many options by listening to the views of each participant regarding the various potential culturally-competent interventions proposed by members and in the end would be able to decide what would work best for them.

The evolvement of participatory approaches in research can also be seen as part of wider developments in social and health care. According to Braye (2000), participatory approaches are enhanced by including involvement of an individual service user, or prospective service user, in their own use of service; involvement in strategic planning for service provision and development; and the development of user-led services (such as Centres for Integrated Living established by disabled people). The trend towards the participation of disabled people in research can be linked with the development of user-involvement, citizenship and consumer participation (Zarb, 1995). The NHS and Community Care Act 1990, for instance, required that local authorities should consult with service users in the review and planning of services (NHS and Community Care Act, 1990; Lloyd *et al.*, 1996).

This perspective overcame the weaknesses of other approaches like 'democratic research' and 'emancipatory action research'. The open dialogue with service users ensures their views and concerns are represented in the definition of problems, prioritisation of needs and in decision-making. Plus the honesty about differences of opinion and how they are affected by the power held by the different parties in the partnership, is likely to produce more balanced feedback since they have been involved in the onset. Thompson (1998) argues that, as a practice principle, participation occurs not only at the micro-level of specific practice situations but also at the wider levels of service

planning, policy development, evaluation and training. In the designing of a culturally-competent intervention, the service framework model will be owned by the general practice, which will ensure appropriate systems and procedures are in place, so that should it be implemented, it can deliver improved diabetes outcomes for their patients. Braye and Preston-Shoot (1995) discuss the whole notion of user involvement particularly in terms of users being in a negotiating position from which power can be exercised and has the potential to achieve its purposes. Braye and Preston-Shoot (1995: 118) summarised the necessary key qualities and characteristics if 'participatory' is to be more than a buzz word and empty rhetoric by developing a list and using the term 'participation' rather than 'involvement' (Box 6.1):

Box 6.1: Qualities and characteristics of participation

- Clarity about what participation is being offered, and what its limits are;
- Participation from the beginning in ways which are central to agency structures and processes but which are also flexible;
- Tangible goals for participation;
- Participation from black and minority perspectives;
- Individual and collective perspectives;
- Provision of time, information, resources and training;
- Openness to advocacy;
- Clear channels of representation and complaint;
- Involvement of key participants, not just some;
- Open agendas;
- Facilitation of attendance.

In addition, the preference and appropriateness of using PR methodology has been encouraged by De Koning and Martin (1996). They stipulate two reasons in support of the growing popularity of participatory approaches. Firstly, the increasing gap between the concepts and models professionals use to understand and interpret reality and the concepts and perspectives of different groups in the community may be narrowed. Secondly, cultural, historical, socio-economic and political factors, which are difficult to

measure, have a crucial influence on the outcomes of interventions and efforts to improve the health of people. With the aim of simplifying the process and the motivation for its application, Chambers (1997) identifies the following key features of breaking down the mystique surrounding participatory research (Box 6.2):

Box 6.2: Chambers (1997) features of breaking down mystique surrounding PR

- Problems researched should be perceived as problems by the community to which the research is directed;
- Helps to develop self-confidence;
- Provides self-reliance and skills within people to whom the research is directed;
- Encourages democratic interaction and the transfer of power to the research participants.

Therefore, PR is based on establishing equality in research relationships, giving more say in research to people who more usually are subjected to research by recognising them as researchers themselves, in the pursuit of answers to questions of daily life struggle and survival. This approach was useful in this study as it enabled the researcher to explore and understand in detail the phenomenon and answered the 'how' and 'why' type questions, whilst taking into consideration how the phenomenon was influenced by the context within which it was situated (Baxter and Jack, 2008).

6.4. Research methods

6.4.1. Study design and methods

A qualitative participatory case study research approach design method was employed. All stages of the study design were developed in consultation with all members of the supervision research team. The DEDICATED Expert Group (made up of patients from target groups and staff from a multidisciplinary team of health workers) and the Warwick Diabetes Research and Education User Group (WDREUG) were also consulted on the design of the study. Access to participants was granted by NHS Coventry, Coventry and

Warwickshire Partnership Trust (CWPT), and George Eliot Hospital NHS Trust. As stated in Chapter Five, ethical approval was granted by National Research Ethics Service (NRES) Committee West Midlands – Solihull, who also gave the researcher permission to interact and conducted informal interviews with participants during participant observations within participating general practices. The service support cost of the study was met by an unrestricted educational grant from Novo Nordisk. Lunch/refreshments were provided during the monthly PR group meetings by Pfizer Pharmaceutical Limited and arranged by the general practice.

6.4.2. Research settings

NHS Coventry, Coventry and Warwickshire Partnership Trust (CWPT), and George Eliot Hospital NHS Trust.

6.4.3. General practice recruitment and inclusion criteria

Recruitment of general practices commenced in December 2011 and ended in April 2012 and all 34 participated general practices in the Coventry General Practice Survey (Chapter Five) were eligible to participate in the study. The recruitment was via a purposive selection based on the findings from the General Practice survey and the geographical location aimed at recruiting three general practices as follows:

- (a) P1 - reporting high performance in culturally-competent diabetes services with high number of EMGs with diabetes (n=1)
- (b) P2 - less performing practices with high number of EMGs with diabetes (n=1)
- (c) P3 - average performing with less EMGs with diabetes (n=1)

This was to be used for benchmarking, in order to inform practices demonstrating lower performance and/or still meeting patients' needs when it is a minority of the population. Based on these criteria, of the 34 general practices that participated in the general

practice survey, 20 met the inclusion criteria; 7 general practices were P1, 5 fitted P2, and 8 general practices met P3 criteria. Fourteen general practices were excluded because their eligibilities could not be determined due to missing data.

An invitation letter and payment invoice (Appendix 8), explaining the study and the general practice's involvement, were sent to each practice manager and to the senior GP of each practice by first class post, followed by electronic copies via email, three days later. Both mailings contained information on how to contact the research team should they be interested in the study or need further clarification. Participants were also informed in the invitation letter that selection was based on a 'first come first serve basis,' and each practice would be paid £500 as appreciation for participating at the end of the study. Each patient would be offered £50 Tesco voucher, if they attended 75 percent of the monthly meetings. Two mailings were posted to the practice and non-respondents had three telephone follow-ups after 2 and 3 and 6 weeks following initial mailings.

6.4.4. Difficulties in recruiting general practices

Despite sending out invitation letters, reminders and follow-up by phone to all the eligible practices, the recruitment process proved challenging, and the response rate remained very poor. A revised recruitment strategy was formulated in line with the ethics approval, in which this researcher liaised with his supervisors for contingency plans and made the third phone calls directly to the practice managers. About two months after the initial invitation letters, two of the practices (one P1 and one P2) invited the researcher to explain the study in more detail to the lead GPs. These meetings gave the practice lead GPs and managers an opportunity to ask questions and be clarified, especially around the

level of disruption to their clinical services. These two practices then agreed to take part in the study.

6.4.5. Withdrawal of general practice

One of the two general practices withdrew after six weeks of commencing the study within their practice. Prior to commencing at the general practice, it had been negotiated with the senior GP, practice manager, and practice nurse that the researcher would spend one full day per week at the practice, which could be split into two half days to ensure effectively working with all staff. However, after six weeks of attending the practice with few opportunities for observing or participating in patient care consultations being facilitated by the practice, a meeting was requested by the researcher to discuss the study and was attended by all three members of the above mentioned staff on 14 May 2012.

At the meeting, the practice decided to withdraw from the study, stating the following:

1. Staff unable to recruit the required two patients for the study,
2. Study is complicated as it involves the researcher observing staff interactions with patients and also undertaking monthly meetings with three staff and two patients,
3. Study not fully understood from onset and not all practice staff favoured their interactions with patients being observed by the researcher,
4. Practice's input in the study is not financially cost effective.

It was acknowledged by both parties that things were not working as planned and because participation was entirely voluntary, the researcher accepted the general practice's withdrawal. Although at the meeting, it was agreed that the data already collected within their practice could be used for the study (provided it did not have any patients' identifiable information), this consent was later withdrawn altogether, sixteen

weeks following participation withdrawal via an email written by the practice manager on 9 September 2012. Therefore their data are not included in the analysis.

6.4.6. Participant recruitment

A purposive sampling method was used to recruit both staff and ethnic minority patients within the recruited general practices. This method was preferred to ensure a variety of staff within each general practice was selected (Bowling, 2009). This process began after the researcher had commenced observations within the participating practices. The staff recruitment process was conducted by each of the lead GP and practice manager whereby staff were purposively given a copy of the invitation letter (Appendix 9) and participant information sheet (PIS) [Appendix 10] and asked to respond directly to the researcher if they were interested in the study. Staff eligibility was assessed by the researcher in consultation with the practice diabetes lead GP and practice manager. The lead GP determined patients' eligibility through information recorded in their health records.

The inclusion criteria were:

- (a) Staff: Any group of professional or administrative worker working with EMGs with diabetes or having responsibilities for delivering diabetes services in the practice and have been employed in current post/team for at least six months. The six month duration restriction was to ensure that staff were familiar with the clinical environment and/or their respective day-to-day role routines.
- (b) Patients: Any adult patients over 18 years old of African Caribbean or South Asian origin, registered with the participating general practice, living with diabetes, able to consent and not otherwise deemed inappropriate by their GP.

Initial contacts of eligible ethnic minority patients to take part in the participatory meetings and/or the semi-structured interviews were carried out by the lead GP for diabetes, in which a copy of the invitation letters (Appendix 11 containing a stamped reply slip and researcher's contacts) and (Appendix 12 - written on behalf of the general practice) and the PIS (Appendix 13) were given to patients identified by the lead GP. The lead GP determined patients' eligibility through information recorded in their health records. As with the staff recruitment process, patients were asked to respond directly to the researcher should they be interested in the study. The initial contact by general practices was deemed appropriate as the patients may have developed a better rapport with their service providers and will be confident in the process and reliability of the study than if it had initially come from the researcher.

6.4.7. Protection of Human Participants Measures: Ethical Considerations and Confidentiality

There were no anticipated risks associated with this study. The research was carried out in accordance with the requirements of the Department of Health's Research Governance Framework (RGF), Good Clinical Practice (GCP, 1996), and the approved Trusts' policies and procedures such as Informed Consent, Risk Assessment, the Protection and the Use of Participant Information and Research Procedure. In the UK, ethical standards make confidentiality a legal requirement for the researcher and advise that if human beings are used as subjects in research, great care must be exercised to ensure their rights are protected (Polit & Hungler, 1995).

This study involved both NHS patients and staff; all participant information was treated with strict confidentiality. All members of the research team were informed of the necessity

of participants' confidentiality in the study, enshrined in the NHS Code of Confidentiality (DH, 2003a) and the Data Protection Act (DH, 1998). It is important to note that the ethical principle that governs all research involving human beings advises that respondents should not be harmed as a result of taking part in a research, and that the participants should give their informed consent (autonomy) to participate in the research (Bowling, 2009). This study conformed to all standards as respect for confidentiality of participants' information is a basic principle of both ethical and effective healthcare practice, because it ensures the patient's privacy and assures public perception of the quality of the healthcare system and its professionals (Vigod *et al.*, 2003). However, Saks et al. (2000) explain that confidentiality may be over-ridden by the researcher's obligation to fulfil another obligation - reporting of an 'at-risk' situation. Participants were thus informed in writing prior to agreeing to participating in the research that if they disclosed information that indicated the welfare of their patients or colleagues or themselves was seriously at risk, then the researcher may have to break this confidentiality. This did not occur throughout this research process.

Prior to commencing the PR with general practices, the researcher met with each of the practice manager and Lead GP for diabetes and a contract (Appendix 14) was signed clarifying the responsibilities of the practice and those of the researcher.

To ensure that participants were fully aware of their rights and responsibilities in the study, the detailed PIS clarified the objectives of the study, assuring them of their confidentiality and of the fact that participation in the study was entirely voluntary and of their right to withdraw at any stage without affecting their NHS care. The PIS also featured commonly asked questions with answers. Once participants were recruited, individual participants'

written consents (Appendices 15 and 16) were obtained prior to commencing all scheduled activities. The process adhered to NRES standards for gaining informed consent.

The participants were assured that:

- (a) Their identities would remain anonymous in all forms of dissemination, codes and where necessary, pseudonyms would be used rather than real names;
- (b) Individual interviews would be conducted in private places, preferably of the participants' choice;
- (c) Original data from the study would be handled only by the researcher or approved personnel and not shared with anyone outside the research team, subject to statutory requirement to disclose;
- (d) Research audiotapes and texts would be secured in a locked filing cabinet in the researcher's office and destroyed in accordance with Good Clinical Practice;
- (e) The only time that their confidentiality would be broken is if they (patients) disclosed information that indicates their welfare is seriously at risk or if serious professional misconduct (in the case of staff) is disclosed. In each situation, the researcher would discuss this with them first. The researcher would then seek advice from his supervisors who are also members of the research team, as to what action (if any) would need to take place.

After data collection, all electronic data were stored on password protected computers, a UHCW NHS Trust password protected laptop used by the researcher as well as UHCW NHS Trust authorised, encrypted and password protected memory sticks. The laptop was stored in a locked cupboard when not in use. All field note diaries (written anonymously),

audio tapes and digital recordings used during participant observations, participatory research meetings and individual interviews were also stored in a secured cupboard within the researcher's office.

All audio and transcribed data were anonymised with pseudonyms used to generate qualitative data reporting and discussion to protect the anonymity of participants. Furthermore, all data used for disseminating the findings or other study reports were also anonymised using appropriate pseudonyms. Only the researcher had access to participants' personal details throughout the study. All participants indicated on their consent form they wished to receive a summary report at the end of the study, and provided their contact details for that purpose.

6.4.8. Developing and building relationships and trust

Relationships are fundamental in PR approaches. Being an outsider with an established approachable, friendly and honest reputation, the researcher had to use previous experience and knowledge from work and studies to earn trust and respect from the practice staff within the first month. This approach enabled him to work effectively with both staff and patients throughout the study duration. His approach of always '*put the patient first in all we do in the NHS*' proved beneficial in developing trusting relationships throughout, especially during the participatory group meetings and interviews as participants freely commented on issues affecting the practice or patient care. However, as a researcher, it was critical to be open and clear about the researcher's and participants' roles within the PR. For example, at PR group meetings, participants were informed that although the researcher had an interest in and theoretical knowledge of

culturally-competent diabetes services, he was a participant as they were and not an expert in their chosen culturally-competent diabetes service being designed.

In the initial meetings, it was acknowledged that all participants had been invited to participate in the study on the basis of their experience, expertise and knowledge of the practice needs and issues affecting ethnic minority patients with diabetes. This was to empower and assure participants, thus building individual confidence to actively participate. Therefore, during the participatory meetings, individual views were sought, opinions considered and incorporated into the designing the interventional framework. Individuals either volunteered or were chosen to provide feedback during and following group work, the researcher as a participant and the facilitator tried to ensure that all individuals were given the opportunity to express their views.

In the process, respect for and appreciation of participants' voluntary will and their diverse expertise in the study were a valuable starting point. Incorporating informal time into each participatory meeting by providing refreshments/lunch fostered mutual relationships during this common talking forum. This also enabled the researcher to further explore individual issues raised at the meeting and to better understand participants, who could be seen chatting with each other, and patients freely interacting with staff. This further added to the trust of one another during audio-recorded meetings.

There were times when some participants were unable to attend the PR meetings. In such instances, an informal one-to-one meeting or telephone conversation was arranged to keep them abreast on what was discussed at the meeting. With meeting dates finalised and agreed at the second meeting, attendance was regular.

6.4.9. Preparing for participatory research and retaining participants

Monthly supervision meetings, interactions with peer researchers, text books and journal articles (Cornwall and Jewkes, 1995; Swain and French, 2004), coupled with interactive tutorials via the Internet prepared the researcher. The ongoing support, especially in motivational training strategies from the supervisory team, with an expert in behavioural medicine and on interventions for people living with long-term conditions, was critical to the success in the process. All these resources gave the researcher confidence to successfully complete the PR.

To retain participants, multiple strategies were used to facilitate participant motivation, such as phoning participants a day before the PR group meetings and sending text messages on the morning of each meeting. Soft drinks were provided during meetings and sandwiches served at the end of each meeting. Networking amongst participants was encouraged and this enabled participants to learn about one another's roles in the community.

6.4.10. Participatory research approach

The PR approach involved:

- (a) Participant observations of interactions amongst general practice staff members and with patients, clinical consultations, professional, administrative contexts and at times taking part in delivering clinical interventions to patients with designated clinical staff;
- (b) Participatory research monthly group meetings;
- (c) Post-participatory semi-structured interviews at the end of the PR group meeting phase; and
- (d) Semi-structured interviews with multilingual link workers.

In designing this study, the researcher was aware of the challenges involved in using participatory research approaches (such as potential ethical dilemma for the researcher) especially when using participant observations as a research method. As such, a 'notice to patients' (Appendix 17) informing them about the research and their rights to exclude the researcher from the consultation should they wish was displayed within the reception area. Patients and staff were aware that they could ask the researcher to leave the consultation room at any stage of their consultation. Furthermore, patients were made aware of the researcher's presence when checking in with the receptionist. By using his effective communication, facilitation and organisational skills from previous roles, the researcher worked in accordance with the practices' local policies and guidelines and also in line with Good Clinical Practice guidelines.

The first three components of PR (participant observations, PR monthly group meetings and post-participatory semi-structured interviews) were conducted from April 2012 to October 2012 followed by semi-structured interviews with two multilingual link workers in January and March 2013. During the initial six weeks of active PR within the general practice, all practice staff were informally interviewed individually by the researcher to understand their roles and the operation of the general practice in general and the management of EMGs with diabetes in particular. The six weeks PR activities comprised one day eight-hour shift on Mondays, where the researcher observed and sometimes participated in interactions between staff and patients during consultation or at the reception. Monday was preferred by both the researcher and Lead GP for diabetes as all practice staff were on duty coupled with more annual diabetes checks. Informal interviews with staff and occasionally with patients were conducted at the end of their consultations

to follow-up interesting issues or ask for clarifications of issues discussed during consultations. Therefore, it was incumbent on the researcher to remain reflexive and critical throughout the participant observation research process, with a sustained focus on understanding and negotiating using critical ethical theories (Truman *et al.*, 2008). All these helped the researcher to engage and understand participants when inviting them informally for interviews. In all cases, verbal consent was obtained prior to engaging with patients about any aspects of their consultations or medical conditions, which was in line with the ethics approval. Research field notes were completed between patient consultations or during coffee/lunch breaks. At the end of the first six weeks, the first PR group meeting was convened with practice staff. The working pattern of the researcher remained the same throughout the study duration, except when PR group meetings were organised out of a Monday to accommodate the needs of the practice and/or participants.

6.4.11. Data collection methods

6.4.11.1. Participant observations as a data collection tool

A review of a decade of observational literature on nursing (Allen, 2004) categorises field roles from the 'detached observer' where the objective was to develop a dispassionate description of nurses' work in an Emergency Call Centre, through to full participation with the aim of reaching an embodied understanding by 'stepping in someone else's shoes' (Savage, 1995). In this regard, Griffiths (2009:18) noted that *'when we observe and then describe what we observe, we start the process of abstraction, picking out from all the many details of life the aspect we want to study.'* She recommends that when observing things such as in clinical settings, using previous knowledge, we should be prepared and open to surprises and look out for what we 'don't expect,' otherwise, we would inevitably see what we expect to see and consequently uncover nothing new, or worse, reinforce

current erroneous knowledge. With this in mind, the researcher as an active participant and observer made comparisons of what has been said or done to what was actually happening during the study duration, whilst making notes on the changes or differences.

This approach was useful in collecting data in naturally occurring behaviours and contexts and it enabled the researcher to question, understand and document how things work. It complemented the study by enriching all the other qualitative data (interviews and participatory meetings) collected and placed the researcher for extended periods of time in an intervention's social milieu to understand interventional interactions from the patients' viewpoint as well (Werner, 2005). All data from this method were collected as field notes (from observations and conversations with both staff and patients) and, where appropriate, were fed back into the PR group meetings described below.

At introduction to the general practice, the researcher was granted verbal permission by all staff to observe all activities within the general practice. Throughout the duration of the study, staff/patients, staff/staff and patients/patients interactions were observed. However, one GP declined to be observed during consultations with patients. The first hour on most Monday mornings, the researcher worked within the reception area, observed all interactions and occasionally took part in directing patients into their consultation rooms or attending to general inquiries. This was usually followed by the researcher working along with the lead GP for diabetes at clinical consultations, unless arrangements had been made for the researcher to work with another GP or practice nurse. The lead GP for diabetes obtained verbal consent from patients in the presence of the researcher whilst two other GPs and the practice nurse asked the receptionist to check with the patients if they would be happy to have their consultation in the presence of the researcher. If the

patient objected, the clinician would request the researcher to leave the consultation room before the patient arrived.

6.4.11.2. Participatory research group meetings

Four staff and three ethnic minority patients consented to take part in the PR group meetings. Within the participating case study general practices, a range of methods and strategies were used for planning, initiating and evaluating discussions and capturing data relating to the culturally-competent diabetes services under investigation. These meetings comprised of eight participants (four practice staff, three ethnic minority patients and the researcher) to discuss their preferred practice foci for designing a culturally-competent diabetes service or care pathways. These were monthly meetings conducted every three to five weeks in the meeting room on the first floor within the general practice, away from clinical areas which are located on the ground floor. This was intentional in order to reduce interruptions. The meeting room was always prepared and laid out in advance by the researcher. Participants were welcomed by the researcher, lunch set out and soft drinks made available during the meetings. Participants and especially patients may have felt they were coming into an environment where they were cared for and valued. These meetings were audiotaped and carried out during lunch hours, each one lasting approximately between 55 and 85 minutes. Each meeting's content was based on previous meetings and sometimes arose during the meetings. Although six meetings were originally planned, the process outlined was completed at the fifth meeting. The initial meeting was aimed at:

- (a) sharing existing evidence from the two systematic reviews and the general practice survey relating to effective culturally-competent diabetes care services;

- (b) identifying and prioritising the content of the practice's perceived most important cultural barriers to ethnic minority patients; and
- (c) engaging the practice staff to identify, prioritise, and initiate the designing of a culturally-competent diabetes service framework that is likely to meet the most achievable goals towards improving cultural competences within the practice to enhance care services to ethnic minority patients with diabetes.

As stated, subsequent meeting agendas were planned to focus on small sets of topics, questions or themes identified from the evidence and the actions arising from the meetings. Each person introduced themselves at the beginning of each meeting. Participants' voluntary participation was reconfirmed and the importance of confidentiality ensured. A chronology of content of the PR group meetings is presented below in the 'result section.'

6.4.11.3. Semi-structured face-to-face interviews and undertaking participants' interviews

Interviews can be described as "conversations with a purpose" (Loffland and Loffland, 1995). Based on the evidence reported in Chapters Two, Three and Five and the researcher's personal and professional insights on diabetes in EMGs, a seven-section interview topic guide was developed for ethnic minority patients (see Appendix 18). There were five and six sections in the topic guides for practice staff and multilingual link worker participants respectively (Appendices 19 and 19A) to provide a level of consistency between interviews, whilst maintaining some flexibility to capture ideas raised by the interviewees (Stone *et al.*, 2013). The interview topic guides were designed to focus the discussion on the phenomena of interest. The first section of the interview focused on close-ended (practical) questions, gathering demographic data from participants and what languages they spoke. This was to ensure accurate labelling of the data by the transcriber

and also in data analysis. The other sections of the semi-structured interviews used mostly open-ended questions focusing on participants' experience of the PR group meetings, diabetes and routine care, being heard, partnership working between ethnic minority patients and staff, and staff training.

To address content validity, the interview topic questions were reviewed for content relevancy, linguistic appropriateness, and clarity (Waltz, *et al.*, 2005). Like with the general practice survey (Chapter Five), the researcher sought input on the questions in the preliminary interview guide from the Warwick Diabetes Research and Education User Group (WDREUG) and the supervision team. Being a topic based interviews, the initial interview with a member of staff provided an opportunity for the researcher to substantiate the appropriateness of the questions and fine-tune the interviewing process. However, as stated above, occasional word changes (not meanings) and probe questions were used, as well as changes to the sequence of the questions in the script to enhance comprehension when explaining the questions in detail for clarity. It has been acknowledged that the researcher has the freedom to alter the sequence of questions, when using semi-structured interviews, and can probe for more information depending on participants' responses, in order to obtain a complete perspective for the phenomena of interest (McCance *et al.*, 2001). These topic-based questions were useful during the interview process to redirect the conversation if needed.

This post-PR semi-structured interviewing process enabled each participant's experience to be explored in depth, which further enhanced the designing of the selected culturally-competent service framework and understanding of issues related to delivering diabetes care to ethnic minority in general. This method was considered to be less threatening and

necessary to give participants the opportunity to discuss issues in more details, especially aspects which they may have found inappropriate to bring to the group settings. Moyser (1998) argued that interviews empower participants into a conversation as they do not feel that they are offered 'right or wrong responses'. Other writers concur and favour the use of a loose guide to direct the respondents in semi-structured interviews (Kvale, 1996; Ring and Danielson, 1997).

Six one-to-one interviews were conducted with participants who took part in the PR group meetings and two MLWs. One PR group staff participant declined to be interviewed, which was respected. All participants chose to be interviewed within the same general practice, with three staff choosing their offices and the patients (n=3) interviewed in a quiet room located on the ground floor of the building. Of the two MLWs, one chose to be interviewed in a quiet room at work and the other at home.

Prior to starting each interview, the researcher checked with each participant if they had any questions and asked each of them to reconfirm their voluntary participation in the study. The researcher also had an informal chat with each of the participants at the end of the interview. This is good practice as it helps participants to feel at ease and build their confidence as well as trust with the researcher (O'Sullivan *et al.*, 1995). The interview duration range was 33 to 74 minutes with the mean being 51 minutes. The researcher was mindful of participant's interest in the study and the therapeutic nature of the conversation with a purpose. Hence, some interviews were shorter in duration than others. In the first interview, the participant chose not to elaborate even after prompting, resulting in a shorter, 33-minutes interview. In another instance, the participant chose to elaborate on their difficulties with managing the practice to ensure better diabetes service provision to

ethnic minority patients in particular and white British patients in general resulting in a longer interview of 74 minutes.

Though it is always advisable to take written notes during a taped interview, it was very difficult to do so during the three patient interviews, as it created a distraction for the researcher, patient or both. Therefore, there was very limited note-taking during the interview, which was restricted to recording use of body language or non-verbal responses, to supplement the interview. It is worth noting that non-verbal communication augments the richness of taped data when extracted from the text (Morse & Field, 1996; Pope and Mays, 2006). To ensure this, the researcher completed a reflective diary following each interview. In addition, if the participant made a reference to something not familiar to the researcher, the meaning of the comment was explored with the participant while making a notation to further explore the contextual meaning of that particular comment.

Two staff interviews were interrupted; in one interview, another member of staff needed an urgent response to an external inquiry. The recording of the interview was stopped and the interviewee took approximately ten minutes to attend to the query. The second interview that was interrupted was carried out in the participant's home. This was interrupted by a family member. Both interruptions slightly interfered with the manner in which the data were collected, such as the flow of conversation and a number of questions had to be repeated. However, the overall aims of the interviews were achieved.

At end of the interview, participants were asked, 'Is there anything else you would like to add.' This last question gave participants the opportunity to summarise answers, express their thoughts and feelings, and clarify and/or elaborate on previous statements.

Overall, data saturation was considered to have been attained after completing all the eight semi-structured interviews, in addition to the participant observations and PR group meetings data collection.

6.4.12. Data management

This section details the manner in which data were gathered, managed, processed and analysed. Following the fieldwork a 'Thank You Letter' was sent to all participants.

6.4.12.1. Use of recording instrument

As stated above, all participants agreed and signed a consent form (Appendices 15 and 16) giving their permission to audio-record the PR meetings and one-to-one interviews. The audio-recording enabled the researcher to maintain regular eye contact with participants during these two research processes and also concentrated on what they were saying rather than continuously taking notes.

6.4.12.2. Use of fieldnotes

Emerson et al. (1995) define fieldnotes in ethnography as 'accounts describing experiences and observations the researcher has made while participating in an intense and involved manner'. They are generally employed by qualitative researchers in addition to other recording methods to try to understand the true perspectives of the phenomenon under investigation, accessing the phenomenon or subject and recording what they observe in an inconspicuous manner. However, one key shortcoming with the use of field notes is they are recorded by an observer and are subject to memory and, possibly, the

conscious or unconscious bias of the researcher (Emerson *et al.*, 1995). According to Charmaz (2006), fieldnotes are often used to record observations and reflections on the data, as part of the reflexive approach to the ongoing analytical process. As noted above, taking fieldnotes, especially at the participant observation, was particularly relevant to this research when noting what participants set out to do and what they actually did, including their non-verbal communication to elaborate on certain questions. It has been argued that using audio recorders does not accurately capture all interaction, such as *'the physical setting, the impressions the observer picks up or the non-verbal communication in an observed interaction'* (Morse and Field, 1996: 91). Therefore, fieldnotes have augmented the richness of overall data analysis of his research. For example, during the second participatory meeting, the meeting room phone rang, the practice manager made a signal that no one should answer it, which was noted and a decision reached to unplug it prior to each subsequent meeting. Furthermore, at one of the one-to-one interviews with a staff participant, an emergency came up requiring their attention and the researcher indicated by a nonverbal signal to the interviewee to attend to the emergency.

6.4.12.3. Transcription of participatory research group meetings and interviews

Recorded information or interviews can be transcribed at different levels, which are why decisions need to be made about how much detail to record (Mishler, 1986). Mishler further argues that transcription is not a simple process because the non-verbal elements of participants in the course of the discussion, such as expressing or emphasising ideas through body movement are difficult to capture. However, it needs to be empathised that the accuracy of the transcripts is vital in qualitative research, in terms of both the questions posed as well as participants' responses (Mishler, 1986).

All audio-recorded meetings and interviews were transcribed verbatim by a contracted professional transcriber within ten days following the meeting or interview, thus letting the data inform subsequent meetings (Fagerli *et al.*, 2005). The transcriber who is experienced in healthcare research, was provided with a list of commonly used medical terms or acronyms, which were likely to appear in the tapes/recordings, such as QOF (for 'Quality and Outcomes Framework') and DNA (for 'did not attend').

All transcriptions were checked for verbatim accuracy by the researcher and any error or missing information included. To preserve participants' confidentiality and anonymity, any identifying features mentioned in the meetings or interviews were removed by the transcriber and rechecked to be so by the researcher.

6.4.13. Data analysis and presentation

6.4.13.1. Use of Computer Package: NVivo 9.2 package

Many computer packages have been developed to assist in the organisation and analysis of qualitative data. Nonetheless, there continues to be debate amongst qualitative researchers as to whether computer packages should be adopted (Seale, 2005; Pope and Mays, 2006). Some qualitative researchers have expressed fears that they will impose a rigid framework upon their analytical process given that they originated in the statistical quantitative paradigm (Seale, 2005). The benefits of using such packages in qualitative research are being increasingly recognised as their assistance in data management facilitates theoretical sampling and "constant comparison" across cases (Bowling, 2009; Seale, 2005). In this study, the data package NVivo 9.2 was used for practical reasons; it facilitated data management by drawing together and highlighting data not initially apparent to the researcher than if manual approaches were employed for coding. A further

advantage of such packages is their transparency, allowing others to see the manner in which the coding was conducted and analysis reached (Green and Thorogood, 2009). Word documents of the transcripts from interviews and participatory meetings were imported onto the computer package. This facilitated data analysis as it enabled the management of large amounts of data in a standardised and transparent way, thus contributing to the “credibility” of the study (Charmaz, 2006). In essence, NVivo 9.2 provided practical tools to make coding quicker and easier for the researcher.

It has been contended that transcripts, fieldnotes or reflective diaries are raw research data and provide only a descriptive record and not explanations (Pope and Mays, 2006). It is therefore the researcher’s responsibility to make sense of the data by sifting and interpreting them. The PR meeting transcripts were coded as ‘PR1 to PR5’ with dates in the order year-month-day and the one-to-one interviews coded as SP1 to SP3 for the staff participants and PP1to PP3 for patient participants, followed by dates (for example 120629SPP1 for transcript of PP1 conducted on 29 June 2012 or 120619SP1 for transcript of SP1), as there were five PR group meetings and eight interviews respectively. These served for quick identification. In both data analyses, listening to the recorders and correcting errors by the transcriber was time-consuming compounded by reading the transcriptions over and over due to the digressions of the participants. Nonetheless, the researcher consulted the fieldnotes/diaries from participant observations and the transcripts of each of the participatory meetings and interviews and read them over and over in order to be fully aware of the content and what was relevant to the research question. Significant statements and phrases pertaining to each participant’s view were then extracted and coded within NVivo. Coding of each transcript was performed individually. Consistency and fullness of the coding was examined before classifying the

data into categories and themes. These categories and themes across all the transcripts from the various data collection methods were collated and re-examined, in order to ensure common categories that were unique. This method of data analysis is described as constant comparative method (Murphy et al. 1998), derived from grounded theory (Barbour, 2001). The data analysis was a continuous iterative process with categorisation fine-tuned to reflect new themes and variations on existing themes. Categorisation is useful in data analysis as it facilitates meaning (Haralambos and Holborn, 2008).

Despite the 'reading of transcripts over and over' being rigorous and labour-intensive, the researcher maintained this approach to ensure integrity of the participants' ideas and experiences at the PR. Data from all three research methods (participant observations, PR meetings and post-participatory research interviews) were coalesced into themes for analysis and presentation within the stages of developing different roles within the selected service framework and other aspects of the study.

6.4.14. Reliability and validity of the data

Morse & Field (1996) have described reliability and validity in qualitative research as the extent to which the research findings represent the reality of the individuals experiencing the phenomenon. However, the conduct of this qualitative case study research created some threats to the reliability and validity of the data (Twinn, 2000, Green and Thorogood, 2009); depth of data collected, audio-recording of the naturally occurring interactions (Hutchby and Wooffitt, 2008) and the researcher's dual role of a researcher and a participant.

In qualitative research, the interpretation of meanings can be subjective in nature and could be seen as erroneous and difficult to achieve. However, through self-reflection and based on the general aim of all qualitative research, the researcher has presented the data from this study to reflect the views of the research participants. With the researcher being an active participant within the research this enabled him to complement the spoken word with observation, thus enhancing the validity and reliability of the data. The themes arising from the data were discussed during research team meetings to reflect the views of participants. Furthermore, a copy of the final findings was sent to all participants, as all had accepted this offer, which was given at the start of the study. The researcher ensured that this happened prior to any publication to give participants the opportunity to comment. It has been argued that the task of interpreting the data should lie with the researcher who seeks the meaning of everyday experience rather than the experiences from an everyday perspective (Giorgi, 1971). This could imply that the researcher would interpret the meanings of participants' descriptions more effectively than the participants themselves.

The chosen diabetes service designed was decided by practice staff and clearly based on their ethnic minority patients' needs. The views of these participants, which are accepted by the researcher as a true representation of their views, were not shaped to suit the researcher's personal opinion relating to this phenomenon studied. Therefore, the researcher strove to ensure the results and the design of the proposed culturally-competent service model from this study would be considered as reliable and a true representation of the views of both ethnic minority patients and practice staff based on their interactions with one another, and be transferable to wider NHS settings. Ryan (1996) advocates that the description of a phenomenon is measured not by the criteria of correctness but by the criteria pertaining to its consequences for real life. In essence, the

general practice selected and prioritised the designing of a model and initiated the process based on the needs of their ethnic minority patients. In effect, the aim of qualitative research is not whether another researcher would discover the same concepts to describe, but whether the findings of an enquiry are worth paying attention to. Therefore the findings from this study should be made public to inform practice and the framework be further validated.

6.5. Results

6.5.1. Description of the participating general practice

This is a two-storey building inner city practice, located in one of the most deprived areas, with health inequalities around diabetes provision in the northern part of the city with mostly council and landlord housing. The ground floor comprises five clinical rooms, reception area, toilet facilities, a waiting area for patients equipped with a TV set screening health related information. The first floor houses four rooms (manager's office, store, data clerk and secretary and the meeting room), as well as a kitchen and toilet facilities. The practice has a population of 5025 patients with the majority having an ethnic minority origin. There are 10 staff (4 are GPs [one partner, 2 salaried and a locum], one practice nurse, one practice manager, 3 receptionists, a secretary, and a data input clerk), of which 3 were South Asians and one was an African-Caribbean. It operates an appointment system (where patients are pre-booked over the phone or in person and allocated a designated clinician), providing care to all types of medical conditions from contraception, child immunisations to all chronic diseases such as diabetes. Business hours are from 08:30-18:30 with a one hour lunch break. However, emergency cases are treated as a priority. Call-backs and home visits are also organised based on clinical need. However,

patients who do not live within the catchment area, as specified by the practice are told upon registration that they cannot require home visits.

6.5.2. Chronology of the research

Across the findings from each of the methods employed in each dimension of the PR, consistent themes emerged that gave insight into cultural and linguistic barriers leading to designing an interventional diabetes service formwork model aimed at improving uptake and better diabetes access to EMGs within the research general practice.

The results are presented in two sections namely:

- I. Chronology of the research (participant observation, PR group meetings and post-participatory research interviews, as well as interviews with multilingual link workers), and
- II. Synthesis of the results based on consistent themes that arose across the different research methods.

Descriptive analyses of the PR process are first presented within each of the three data collection methods with a few illustrations (Section I). The data emerging from the PR process have been thematically analysed with full data illustrations presented within the synthesis section below (Section II).

6.5.2.1. Participant observations

The participant observation was a continuous process, which lasted for seven months (April to October 2012). Throughout this period, which involved non-participant and participant observations, patients honouring appointments were quickly checked in by the

receptionists and asked to sit in the waiting area until they were called in by their allocated healthcare professional. Patients' consultations with a GP ranged from 4 to 12 minutes, averaging eight minutes per consultation. The allocated time of consultation with the nurse depended on the clinical procedure; for example, an annual diabetes checks appointment was allocated 30 minutes.

Three hundred and twenty-one clinical consultations or procedures were observed by this researcher in which 46% (n=148) involved ethnic minority patients, with the researcher actively participating in 96 consultations, 51 involving ethnic minority patients. The activities performed by the researcher in the presence of a general practice clinician included taking patients' blood pressure (n=49) or blood glucose (n=36), measuring weight (n=20), the rest (n=43) involved general advice on diabetes self-management and care. Eighteen percent (n=9) of the ethnic minorities consultations were with a nurse and the rest with the GPs. During this duration, both strongly evidence-based culturally competent and less evidence-based culturally competent practices were observed. For example, some ethnic minority patients with cultural differences were consulted by healthcare professionals from the same ethnic backgrounds, thereby ensuring cultural and linguistic concordances. However, there was also evidence of unhelpful/less culturally appropriate practices, which included the use of children to interpret for their parents as well as patients with language barriers, in a consultation without the use of interpreters.

In most of the informal interviews carried out with ethnic minority patients, they reported being satisfied with their care most of the time. An illustration was given by a 66-year old South Asian patient with type 2 diabetes, which is well controlled on tablets. The patient presented with a fungal infection, had changed address two years ago (6 miles away from

the practice - out of the practice's catchment area), but still maintained the practice, which she has used for several years. When asked after her consultation 'why do you travel this far when you can register with another surgery closer to you?' the patient responded:

"They are very good here, from the receptionists to the doctors...Doctor [name of doctor] is like my son, he speaks my language and he is very caring and looks after me very well. It's long that I have to travel to come here but I take the bus. I haven't visited the practice for a long time, I felt desperate missing the bus twice today, but I said I must come and see him [Doctor] about this [pointing to the fungal infections around her left waist], even though I'll be late. I told the receptionist when I arrived here what has happened and she talked to the doctor [name of doctor], who agreed to see me. Yes, they are good people." [Female patient, Participant observation notes dated 20/08/2012].

However, cultural differences between patients and practice staff added challenges in the clinical setting. These challenges included disagreements and misunderstandings between patients and healthcare professionals, due to cultural and language differences, with patients sometimes having to rebook for their appointments as it was not clinically safe for the clinician to carry out consultation with the patients. An example relating to language barriers involved a Polish lady in her late 60s who booked to have a diabetes annual review with the nurse. The nurse reported that a Polish interpreter had been booked. However, the interpreter did not arrive. When contacted by the receptionist, the booking office reported that the interpreter had been doubled booked and the patient had to be sent away without consulting and a new appointment offered.

Three weeks later, the same Polish lady came for another elective appointment, this time with the GP and again, an interpreter assumingly booked, failed to arrive. However, this patient was seen by the GP who was aware of the patient's negative experience three weeks ago. This GP tried to use sign language and repetition of words to the patient such as 'Have you got pain?' 'Do you need more tablets?' and then issued the patient with a repeat prescription. Exploring the incident with the GP after consultation, the GP

acknowledged that *'it was neither satisfactory nor a safe practice.'* In justifying the rationale for repeat prescription, the GP said:

'As you observed, I checked the patient's medical records and found that the patient was running out of medication' [HCP 1, Participant observation notes dated 23/07/2012].

Commitment to religion and low health literacy rates were also witnessed. An example of a helpful practice observed related to 'commitment to religion'; a Muslim gentleman in his late 40s who, was on insulin and metformin twice a day, wanted to fast during Ramadan. The diabetes control of this patient appeared poor based on discussion with patient and GP, which was further confirmed by a random finger pricked blood glucose check performed by this researcher. This patient had come in and told the GP that he wanted to stop the insulin and continue on the tablets only. Both GP and this researcher explained to the patient the negative impact this would have on his diabetes control. However, the patient was determined to fast as according to him, his diabetes was given by Allah and the same Allah was going to keep him safe during fasting. Following a lengthy discussion with the patient, it was successfully resolved and the patient's insulin was changed to twice a day (after sunset and prior to sunrise), which met his religious practice during Ramadan.

As mentioned above, other evidence-based culturally competent and unhelpful practices observed during participant observations are presented in the 'synthesis of results section II', based on emerged themes.

6.5.2.2. Participatory group meetings

This section presents meeting attendance rates, characteristics of participants, the chronology of the meetings, and sets out the activities at each meeting with a few illustrations.

6.5.2.2.1. Participatory meeting attendance rates

The table below shows attendance at the meeting and code-based initials have been used to preserve participants' identities. Two participants had 100% (n=4, 5) attendance rate, one had 50% and the overall average was 72% (see Table 6.1).

Table 6.1: Participatory research meeting (PRM) attendance rates

Participant	PRM1	PRM2	PRM3	PRM4	PRM5	Total
HCP 1	Yes	Yes	Yes	Yes	Yes	100% (n=5)
Admin staff 1	Yes	Yes	No	Yes	Yes	80% (n=4)
HCP 2	No	Yes	No	No	No	20% (n=1)
Admin staff 2	Yes	Yes	Yes	Yes	No	80% (n=4)
Patient 1	N/A	Yes	Yes	No	Yes	75% (n=3)
Patient 2	N/A	No	Yes	No	Yes	50% (n=2)
Patient 3	N/A	Yes	Yes	Yes	Yes	100% (n=4)
Total	75% (n=3)	86% (n=6)	71% (n=5)	57% (n=4)	71% (n=5)	72%

HCP = Healthcare professional, N/A = Not applicable

6.5.2.2.2. Characteristics of participants

The characteristics of the participants at each of the participatory meetings and post-participatory interviews were captured through self-introduction and practical question responses at the one-to-one interview sessions aimed at verifying the sample and contextualising the discussion. These are summarised in Table 6.2. The youngest participant was 34 years old and the oldest 71 years with an average age of 56 years. Five of the participants were female (2 patients and 3 staff) and 2 were male (a patient and a staff member). Four participants were ethnic minorities and three were white British. One participant spoke 4 languages including English, another spoke 3 languages, three of the participants spoken 2 languages and two spoke English only. The two multilingual link workers who took part in the interviews were both female employees whose average age was 52 years. Both participants spoke four languages including English.

Table 6.2: Characteristics of participants (n=9) in both PR group meetings and one-to-one interviews

Participant & gender	Age	Ethnicity	Professional discipline	Language(s) spoken	Diabetes experience
Patient 1 (male)	56	Indian	Engineer	English, Gujarati & Hindi	<ol style="list-style-type: none"> 1) Employee engineer who has been living in the UK for 34 years 2) Diagnosed with diabetes 9 years ago and reporting self-managing it well 3) Helps other people with diabetes within his community, e.g. at the temple to raise awareness 4) Empowered to self-manage diabetes by practice and hospital healthcare professionals
Patient 2 (female)	70	African Caribbean	Retired auxiliary nurse	English	<ol style="list-style-type: none"> 1) Living in the UK for 57 years 2) Known to have diabetes for 10 years 3) Managing diabetes with tablets and diet 4) Educated to self-manage diabetes by practice nurse and during consultation with GP 5) Reported good understanding of diabetes and its complications 6) Aware of dietary needs and lifestyle changes
Patient 3 (female)	71	African Caribbean	Retired nurse	English, English Pidgin	<ol style="list-style-type: none"> 1) Retired nurse (living in UK for 46 years) who had worked as RGN for with patients with diabetes and within Ophthalmology for 40 years 2) Diagnosed with diabetes 11 years ago with good diabetes self-management 3) Attends health promotion workshops in diabetes and lifestyle changes, e.g. gym and exercise classes 4) Attended diabetes related refresher courses for employment to self-manage 5) Empowered to self-manage diabetes by practice and hospital healthcare professionals, in addition to own reading.
Admin staff 1 (female)	50	White British	Practice manager	English and little French	<ol style="list-style-type: none"> 1) Employed by the same practice for 18 years, previously as a receptionist 2) Practice manager for 8 years 3) Responsible for all operational functioning of the practice 4) No direct training in diabetes but ensures QOF

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					aspects of diabetes are met.
Admin staff 2 (female)*	63*	White British	Receptionist	English	<ol style="list-style-type: none"> 1) General practice receptionist who has worked within general practice for over 30 years 2) Books patients with diabetes to see respective healthcare professionals 3) Takes information such as blood glucose reading and pass on to clinical staff to act. 4) Reported awareness of prioritisation should a patient with diabetes need emergency care.
HCP 1 (male)	34	Indian	GP	English, Hindi, Telugu and Kannada	<ol style="list-style-type: none"> 1) Qualified medical Dr for 12 years 2) GP for 7 years 3) GPwSI in diabetes 4) Lead for diabetes within the practice 5) Currently undertaking MSc in diabetes care 6) Attends regular diabetes update courses and meetings 7) Self-updates in diabetes via online and appropriate journals.
HCP 2 (female)	59	White British	Practice nurse	English & Arabic	<ol style="list-style-type: none"> 1) Sole senior practice nurse 2) Qualified as a RGN for 39 years 3) Working as a practice nurse for 14 years 4) Worked as nurse in Saudi Arabia for 10 years within Emergency & diabetes department. 5) Delivering diabetes care and education to all patient types with diabetes within the practice 6) Attends regular diabetes updates provided by PLT team 7) Additional self-updates in diabetes via online and appropriate journals.
MLW 1 (female)+	48	Asian Indian	EPP manager / MLW	English, Hindi, Punjabi and Urdu.	<ol style="list-style-type: none"> 1) Qualified community worker who had worked in various roles, Expert patient programme manager for 8 years, health promotion specialist (black and minority ethnic communities) for 4 years, and diabetes multilingual link worker for 2 years 2) Leads the expert patient programme for all chronic conditions, such as diabetes and depression in Coventry 3) Trainer of trainees in the prescriptive EPP course in various ethnic languages (Hindi, Punjabi and Urdu)

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					<ul style="list-style-type: none"> 4) Attended the Warwick University certificate in diabetes 5) Organise educational seminars on diabetes, raising awareness about diabetes and empowering patients to self-manage their diabetes 6) Delivers diabetes patient education in 4 different languages (one-to-one or group settings) to EMGs with challenging behaviours, using posters, audio cassettes in different languages and presentations 7) Educate patients on how to use glucose meters and insulin pens in their first language. 8) Acts as intermediary between patients and healthcare professionals in clinical matters.
MLW2 (female)+	54	Asian Pakistani	Multilingual co-worker	English, Punjabi, Hindi and Urdu	<ul style="list-style-type: none"> 1) Multilingual co-worker with 10 years' experience working with patients with diabetes from EMGs 2) Working with multidisciplinary healthcare professionals and ethnic minority patients and advising on cultural differences that may require particular sensitivity in delivering services across departments 3) Although mostly acts as intermediary between patients and staff, sometimes directly provide some aspects of care and treatment in support of programmes of therapy and intervention supervised by qualified staff, such as guiding and reminding patients to inject their insulin 4) Teaching patients in their first language how to prick their fingers to check blood glucose 5) Interpreting during clinical consultations and in other milieu due to language differences between patients and staff 6) Working with patients from minority ethnic groups to help them access diabetes services and other such as PALS. 7) Organise diabetes education workshops and participating its delivery.

* Did not participate in one-to-one interview + Multilingual Link Worker

6.5.2.2.3. Chronology of the participatory research group meetings

The chronology of the meetings and meeting contents are shown in the Table 6.3 below based on the sequence of the unfolded events throughout the meetings. One PR group meeting which was planned for 25 June 2012 had to be rescheduled for 29 June due to an emergency requiring the practice and external stakeholders.

Table 6.3: Chronology of the participatory research meetings

<p>(a) Meeting</p> <p>(b) Date</p> <p>(c) Attendees (n)</p> <p>(d) Duration (minutes)</p>	Meeting content
<p>(a) Meeting 1</p> <p>(b) 28:05:2012</p> <p>(c) n= 3 staff participants</p> <p>(d) 55 minutes</p>	<ol style="list-style-type: none"> 1) Self-introduction 2) DEDICATED Project update and study aims 3) Diabetes culturally-competent diabetes service priorities of the practice listed by staff included: diabetes leaflets in different ethnic minority languages, audio-video diabetes literature in different ethnic languages, dietitian with experience in ethnic minority foods, diabetes group education for EMGs within the practice, Ramadan clinics, and Multilingual Link Worker (MLW), and MLW was unanimously chosen 4) Exploring the reasons for choosing the MLW service 5) Will the service MLW be paid or voluntary and how often would general practice require this service? 6) Patient benefits of the MLW service 7) Priority languages of patients within the practice 8) Skills and experience of the MLW 9) How to use MLW to help the practice provide better diabetes services to different ethnic minority patients with language or cultural differences within the practice 10) Diabetes training needs of the MLW and their trainers 11) Homework to all participants: (a) Where can we get an MLW in Coventry? (b) During your consultations with patients or meetings with family or friends who have language or cultural issues, check if they believe they can benefit from the use of an MLW.
<p>(a) Meeting 2</p> <p>(b) 29:06:2012</p> <p>(c) n=6</p> <p>(d) 76 minutes</p>	<ol style="list-style-type: none"> 1) Self-introduction 2) Summary of last meeting from researcher where participants were briefed on why/how MLW was chosen, and given each patient participant the opportunity to view their opinion and/or suggest alternatives 3) Review homework 4) Sharing previous experiences of linguistic differences between patients and staff 5) Description of current practice relating to linguistic difference between staff and patients 6) List the ethnic minority languages needed by the practice and the type of MLW required 7) Group work: (a) in groups of two or three (staff and patients (five to eight minutes), consider the situation that the MLW is (i) volunteer (not paid); what are the advantages and disadvantages, (ii) a paid employee, what are the advantages and disadvantages? (iii) living locally (within 10 to 15 minutes' walk to the practice), what are the advantages and disadvantages. (b) For patient participants only, imagine that you didn't speak English, what aspects of your diabetes would you want the MLW to help you with (educate)? For staff, what aspects of diabetes self-management must the patient

	<p>know in order to keep control of their diabetes?</p> <ol style="list-style-type: none"> 8) Feedback from group leads followed by further comments/group discussion relating to the questions 9) Discuss other services the MLW can provide besides liaison and interpretation 10) Discuss the advantages of clinical information to help you manage your diabetes coming directly from your clinician and that from an intermediary, such as an MLW, would you prefer information to help you manage your diabetes come direct from skilful MLW or would you prefer the MLW to always act as an intermediary by taking messages from the doctor or nurse and feedback to you? 11) Skills and experiences of a skilful MLW and training and level of clinical knowledge 12) Specific training: what is DM, weight loss, BMI and etc.? 13) What's working well in your practice that you would like to see continue with regard to managing patients with language and/or cultural issues? 14) Possibilities of joint working with nearby practices to employ different MLWs to tailor diabetes care to individual needs of ethnic minority populations 15) Identifying the linguistic needs of patients and escalating at the point of patient's registration and/or booking for elective appointments 16) What can the practice database, VISION, do to flag up patients with linguistic and cultural differences? 17) Working time of MLW: can elective diabetes clinics/appointments be put on one day? What are the advantages and disadvantages? 18) Homework: (a) For patient participants, consider yourself as the patient who doesn't speak the language of the healthcare provider, and you are in need of medical care, how would you feel if no one can understand what your issues are in order to help you? (b) For staff, during your consultations with patients or meetings with family friends, find out their frustrations/experiences when they go to a foreign country (where the main language is different from their first language) and need medical care or general assistance.
<p>(a) Meeting 3 (b) 23:07:2012 (c) n=5 (d) 51.5 minutes</p>	<ol style="list-style-type: none"> 1) Self-introduction 2) Summary of last meeting from researcher 3) Review homework 4) Advantages and disadvantages of using MLW and a family member or friend 5) Group Work (5 to 10 minutes): (a) Suppose your practice can only employ one MLW who speaks only three of the South Asian languages (Punjabi, Hindi and Gujarati), two nearby practices (A and B) can also employ a MLW each, Practice A MLW can speak Bengali, Urdhu, and Farsi and Practice B MLW can speak Polish, French and Arabic. (i) How can you effectively use your MLW to ensure he/she is meeting the needs of your patient groups who speak these three languages (Punjabi, Hindi and Gujarati)? (ii) How would you ensure that the diabetes needs of your patients who speak only Bengali or Urdhu or Farsi or Polish or French or Arabic are met? (iii) How can the three practices work effectively together to ensure the THREE Link Workers are effectively meeting the needs of patients with

	<p>diabetes within these three practices? (b) Discuss the advantages and disadvantages of booking elective diabetes clinics/appointments of specific ethnic groups who do not speak English on same day and bringing in the specific Link Worker on those days to assist. (c) How will the need for a MLW be identified when booking patients' appointments?</p> <p>6) Publicise the availability of a MLW within the practice</p> <p>7) Homework: Practice manager to liaise with practice staff to write: (a) Job Description (including person specification) for a paid MLW.</p>
<p>(a) Meeting 4</p> <p>(b) 13:08:2012</p> <p>(c) n=4</p> <p>(d) 61 minutes</p>	<ol style="list-style-type: none"> 1) Self-introduction 2) Summary of last meeting by the researcher 3) Review homework 4) Views of participants on the number of MLWs the practice can employ and why, and number of volunteering MLWs needed by the practice want and why 5) Who will be direct Line manager of both paid and volunteer MLWs 6) Group work (10 minutes): In groups of two, discuss and make notes on the following and feedback to the group: How would your practice go about recruiting appropriate MLWs? Consider: (i) What language barriers exist within your practice and which of these languages will benefit patient care most? (ii) What language skills must the MLW(s) have? (iii) Group the languages into two or three as you would like the MLWs to speak (iv) Where can you find someone who speaks these languages? (v) How and where can the advertisement be made? (vi) What initial skills/qualifications should the paid MLW have and why? (vii) What initial skills/qualifications should the volunteer MLW have and why? (viii) How will the linguistic competencies of the MLW be assessed? (ix) How long (weeks) will the induction period be? (x) How long should the initial contract be or should it be permanent? (xi) How many weeks should there be for MLW induction (overshadowing staff)? 7) Detailed feedback and discussion on the above assignment 8) Type of specific additional in-house training that would be offered to both MLWs 9) How to engage other practices and sell the vision/idea of using MLWs 10) How will you sell this model to the healthcare commissioners or influence them to consider its commissioning? 11) Potential risks in sharing MLWs with other practices and ways of minimising the risk 12) Advantages/disadvantages of booking elective diabetes clinics/appointments of specific EMGs who do not speak English on particular days 13) Homework: Practice manager and receptionist to revisit the practice list to establish and present these at the next meeting. Total number of patients with (a) diabetes (b) ethnic minority patients with diabetes (c) ethnic minority with diabetes and language or cultural differences (d) based on the priority of languages, put down the number of patients who speak specific languages, taking into consideration those with language barriers.

<p>(a) Meeting 5 (b) 07:09:2012 (c) n=5 (d) 60 minutes</p>	<ol style="list-style-type: none"> 1) Self-introduction 2) Summary of last meeting by researcher 3) Review homework 4) Group work as detailed in Box 6.3 5) Three priority ethnic languages of patients within the practice to determine kind of MLW 6) Preferences of language spoken by the required two MLW volunteers 7) If MLW model works well for your practice, how would you publicise the service to other practices; if you don't want to share it, why not? 8) If there is a clinical need for MLW, what can the practice do if the commissioning board refuses to commission it? 9) Challenges in sustaining the MLW service 10) Will your practice like the MLW to set up specific support groups for ethnic minority with diabetes within the practice or elsewhere and why? 11) Be safe whilst fasting - Do you have clinical issues with the Muslim patients, such as fasting during Ramadan and not complying with their treatments? 12) What are your thoughts if the LW was SA origin, and is able to organise some advice/education sessions so that doctor and/or nurse could give out information to these patients about medication, insulin or even translate information in their languages? 13) Organising multi-cultural events, what type of information needs to be translated and in which multi-ethnic languages, will the patients actually read them? 14) List five priority benefits of having an MLW within your practice 15) Revisit participants' thoughts about sharing good practice with colleagues and/or with other practices? 16) Revisit VISION database: currently your patients are not reminded about their clinical appointments, do think sending them text alerts a day before their appointments could be useful, how and why? 17) What are your worries/concerns in implementing this text alert service within your practices? 18) What are your worries/concerns about implementing the MLW model within your practices? 19) What would like happen with this work? 20) Is there anything you would like to add regarding everything we have discussed on the MLW model? 21) Is there anything you are concerned with regarding the whole process? 22) Words of appreciation to all participants, reminder to arrange post participatory one-to-one interviews 23) Lunch and networking.
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6.5.2.2.4. Participatory Research Meeting One

This meeting was organised to explore and understand practice staff opinions. It was also an opportunity to share key findings from two systematic reviews reported in Chapters Two and Three as well as findings from the General Practice survey (Chapter Five). This enabled staff to reflect, identify and explore cultural issues within their practice, and prioritise one culturally-competent diabetes service, which could help to improve the diabetes services provided to their ethnic minority patients. The researcher used existing evidence from the above mentioned three studies to inform participants about existing interventions and their impact on diabetes patients' outcomes. Subsequently, the participants selected six potential culturally-competent services (see Table 6.3, Meeting 1). However, due to limited time available to complete the study, the researcher advised them to prioritise and select only one service out of the six. The participants unanimously agreed to focus on designing a multilingual link worker model. Furthermore, during the discussions, it was suggested that a multilingual link worker could in fact facilitate some of the other five suggested strategies such as providing leaflets and audio visual materials in appropriate languages as well as delivering diabetes group education to the ethnic minority patients within their practice. They justified their choice and how it would benefit the practice to provide enhanced diabetes care services to their ethnic minority populations (see illustrations in the synthesis section II below).

Patient participants were not invited to this meeting. During participant observations, all staff participants felt that designing any culturally-competent diabetes service for the practice would be a service-driven activity (led by staff) rather than a patient-focused one. Therefore, the patient participants would not be fully aware of the cultural issues

experienced by staff within their practice. Initially meeting as a staff group would enable them to discuss openly regarding the commonly encountered cultural issues experienced with their ethnic minority patients, discuss them in order to reach consensus. Therefore, the staff participants felt this meeting was necessary to map out the main cultural issues perceived by them as hindrances to tailoring diabetes service delivery to the individual needs of ethnic minority patients with diabetes within their practice. An illustration was given by one participant a week before this meeting:

"I think we [staff] need to have a meeting without the patients first to decide what would be most important for the patients....we know what the cultural and language issues are, but as group, we brainstorm, also you know the literature in this area, this might help. Not that we don't want their [patients'] input." [HCP 1, Participant observation notes dated 21/05/2012].

The researcher was aware of the ethical dilemma this may pose for excluding the patient participants. Therefore, an agreement was reached between staff participants and the researcher that should a decision be reached on a priority service at the first meeting, this would be presented at the second PR group meeting and patient participants would be given the opportunity to comment and add any other services they deemed would improve diabetes care service provision to ethnic minority people within their practice. Should there be additions, a final decision would be reached by a secret ballot and the decision would be respected.

The meeting began with the researcher explaining the house-keeping rules and the importance of maintaining confidentiality. In circular seating arrangement, participants introduced themselves by stating their full names, ethnicity and professional roles as well as something about their everyday life and experience in providing services to ethnic minority patients with diabetes.

HCP 1's introduction illustrates a typical example:

'I'm [name]; I'm a GP for seven years. I'm Indian by origin; I speak English, Hindi, Telugu and Kannada. I've been here [name of practice] for the past five years and my special interest is diabetes. I do nine diabetes sessions and cover full time.' I like watching and playing Cricket.'

All participants introduced themselves and shared their experiences with ethnic minority patients. After introduction, the meeting concentrated on determining the culturally-competent diabetes service and justifying the rationales. During the first 15 minutes, participants listed the following six potential culturally-competent diabetes services as priorities for their practice: diabetes leaflets in different ethnic languages, dietitian with experience in ethnic minority foods, audio-video diabetes literature in different ethnic languages, prescriptive culturally-competent education programmes for ethnic minority patients with diabetes, Ramadan clinics in patient's first language in the community helping to adjust patient's medication and other lifestyle changes to meet their religious commitment, and Multilingual Link Worker (MLW) (paid and volunteer) to facilitate elective diabetes clinic appointments for EMGs with cultural and linguistic differences. MLW was unanimously chosen. The meeting then moved on to discuss the reasons for choosing the designing of the MLW framework and how this could benefit their practice, as well as other ideas which spontaneously arose (see meeting 1 sequence of events in Table 6.3 above).

To stimulate participants and enable them to reflect, they were asked to individually complete an assignment at home, relating to the MLW and then provide feedback at the next meeting (see Meeting 1, Table 6.3, Item 11).

6.5.2.2.5. Participatory Research Meeting Two

A summary of the discussion from the previous meeting was presented to the group. Sitting arrangements were the same as in the first meeting and self- introduction was made especially as the patient participants were attending for the first time and also in order to assist the transcriber. The two patient participants present were given the opportunity to offer their opinion regarding the proposed MLW service, with one of them [Patient 1], who equally supported the MLW service, adding an ethnic minority dietitian to the list but independently and quickly changed their view. Therefore, the designing of a MLW service framework model was unanimously adopted for this PR.

Homework was discussed, and all staff participants reported having completed the assignment. They also reported that they had checked with Coventry Primary Care Trust (PCT) and there was no MLW service in place. They further reported that most of their interactions with patients and family members suggested that these contacts felt that a MLW service would resolve some of the problems, especially relating to language barriers found in general practices. Thereafter, the meeting focused on exploring the Meeting 2 content (Table 6.3), which arose during the discussion.

An interesting group work discussion was on: *‘for what aspects of your diabetes care should the patients with diabetes want help or education from an MLW and the aspects of diabetes self-management that the patient should have in order to control their diabetes?’* as well as *‘the kind of diabetes skills and experience the MLW should have.’*

After exploring the full meeting content, participants were given an exercise as homework (see Table 6.3, Meeting 2, Item 18), which emerged as a consequence of the discussion during the meeting and assimilated by the researcher for homework.

6.5.2.2.6. Participatory Research Meeting Three

The meeting reviewed the activities of the previous meeting and discussed the homework. The PR discussions then led to group discussion by exploring the group work in Item 5 of the meeting content in Table 6.3, which had emerged during earlier group discussion.

These questions generated an interesting debate amongst the members of each group based on feedback from the nominated group leaders and further discussion in the joint group about collaboration working and sharing of good practice. These aspects are illustrated with data in the synthesis (section II below) of emerged themes.

There was a view of what the role of an MLW should be. Following the discussion, Admin Staff 1 was nominated to liaise with participants to draft a job description, which should include the specifications for the MLW (see activity in Item 7 of Table 6.3). Participants were informed that this assignment would be presented and discussed at the next meeting.

6.5.2.2.7. Participatory Research Meeting Four

At this meeting, and as usual, a recap of the previous meeting was presented by the researcher and the homework exercise explored in-depth. Due to issues arising from previous discussions, the focus was then redirected to:

1. How many MLWs will your practice want to employ and why?
2. How many volunteer MLWs does your practice want and why?
3. Who within the practice will be responsible for the MLWs?
4. To whom will they be accountable?

On the first two inquiries, there were no conclusive responses. The number ranged from one to three. One participant [Admin staff 1] said:

“Realistically, two”

This response was concurred by another participant:

‘Yes, two’ [HCP 1]

With regard to the volunteer MLW, after thorough brainstorming within the group, [Admin Staff 1] had this to say:

‘If there were voluntary multilingual link workers, then we’d be opened up to whoever wanted to come and do it; however not many would be available. We always grab at whatever is going free.’

When financial implications were discussed, [Admin staff 1] who is responsible for managing the practice’s budget changed her earlier response in the meeting and said:

“In realistic terms, we [practice] will need one paid and two voluntary multilingual link workers and we would hope that it would be the same ones consecutively.”

The research participants concluded that both MLWs should be line managed by the practice manager but accountable to the lead GP.

The rest of meeting content was successfully discussed. Following discussion within the group and in order to obtain accurate figures of EMGs with diabetes who may be experiencing cultural and language barriers, Admin staff 1 and Admin staff 2 were nominated and assigned to complete the homework on Item 13 of Meeting 4, Table 6.3. This assignment was expected to be presented at next PR group meeting.

6.5.2.2.8. Participatory Research Meeting Five

During the fourth PR group meeting, participants were made aware of the possible end to data collection for this phase of the study pending adequate data gathering at the fifth meeting. Therefore, this meeting was aimed at perfecting the multilingual link worker job description, establishing how the post can be funded and how suitable candidates can be recruited. It also explored uncertainty on issues where limited data had been collected and/or those that were not fully understood by the researcher. To achieve these, the homework was discussed. However, the two assigned participants had not looked at the assignment in detail as illustrated by one of them:

“I thought I was going to do it [homework] but got tied down with other stuff...but we already know these people and their languages, isn't it?” [Admin Staff 1].

Due to lack of accurate information, which would have been obtained from the homework, this assignment was briefly discussed. Admin Staff 1 agreed to provide the accurate data to this researcher at a later date. However, these data were not received after two follow-up emails.

Following the homework activity, the focus of participants was redirected to the contents of the meeting (Items 4-21, Table 6.3), which have emerged during previous and current discussions, and needed further group exploration. First, a 10 minute group work activity (Box 6.3) in groups of 2 or 3 was completed:

Box 6.3: Exploring ways and means of recruiting a suitable MLW

1. What qualifications and language skills must the Link Worker(s) have?
2. How and where can the advertisement be made?
3. What initial skills/qualifications should the paid Link Worker have and why?
4. What specialist skills should the link work have?
5. How will the linguistic competencies of the Link Worker be assessed?
6. How long (weeks) will the induction period be?

Following detailed feedback and further discussions relating to the questions, the participants reverted to the meeting content, in addition to addressing specific questions (Box 6.4) relating to the challenges that may be involving in sustaining the MLW should it be commissioned (Item 9, Table 6.3). Data illustrations are given in the synthesis section II.

Box 6.4: Challenges in sustaining the multilingual link worker framework

1. Should your practice adopt the MLW model, how will cost effectiveness of the service and benefits to patient care be evaluated?
2. If it works, how will you publicise the service to other practices, and if you don't want to share it, why not?
3. If the practice sees the benefit of the MLW service, but clinical commissioning groups refuse to sustain the service, what can the practice do?
4. If there were more than one MLW, will you like to see them set up specific support groups for ethnic minority patients with diabetes within the practice or elsewhere and why?

As a final MLW draft job description and person specification were not agreed by the group, the researcher was assigned to review the PR meetings audios and revise the previous proposed version and send it to all participants to validate. This concluded the PR group meetings and participants were asked to contact the researcher to book dates and venues for their one-to-one post-participatory research interviews. The participants during the meeting appeared relaxed and continued to chat after the end of the formal meeting.

6.5.2.3. Semi-structured face-to-face interviews with practice staff and patients

The aim of the post-participatory research interviews was to give participants the opportunity to share their experience during the PR group meetings and to air any aspects of the research which they could not offer during the group meetings, in addition to their personal knowledge and training around diabetes and diabetes self-management. All six participants reported that they did not experience any frustrating moments throughout the PR group meeting phase and had enjoyed the entire process,

especially listening to and respecting the views of everyone during the group meetings. They expressed hope that their effort and views in designing the framework would be put into practice to benefit ethnic minority patients with cultural barriers. A typical illustration was given by one patient participant:

“It was a very good response from that meeting [PR group meeting]. When the discussion was going round, everybody had a chance to speak their mind up and everybody had their own views and also my view as well about the Link Worker and it was being taken down from everybody...The good thing about this meeting was that once we found out what was the difficulty arising from the ethnic minorities in the surgery and the area and what difficulties they were experiencing for diabetes and decided to establish a Link Worker service that will be useful for these people, everyone started sharing their views about it...I found out and if this surgery can find a Link Worker, which is useful to everybody, that’s very good for everyone, it will be, if they can find one, which is useful for all the diabetic persons in the area... that Link Worker can go with certain people and on a one-to-one basis and find out what are their experiences and what difficulties they are experiencing and help them, yes, this is my hope” [Patient 1, one-to-one interview].

These views were also echoed by another participant:

“I think the meetings (PR) were very good. I think it was interesting that we had patient participation because it’s always good to hear what our patients actually think of the services we’re providing. I think what was felt was that ideally, all surgeries should have a Link Worker, or areas should have Link Workers attached to the surgeries that help with the management of long-term conditions and especially the diabetes. I think we all felt that, including our patients, the representatives that we had at the meeting. Like I say, I think as well, sort of those patient representatives got to understand a little bit more of how things are run in surgery, what services are actually available. I think they got to hear about a little bit more, which most of the population don’t hear about, which is, things like resources and funding, and can help enlighten other patients.” [Admin Staff 1, one-to-one interview].

As with the PR group meetings, other results from the one-to-one participant interviews are reported in the synthesis of themes section II below.

6.5.2.4. Semi-structured interviews with Multilingual Link Workers (MLWs)

The purpose of carrying out interviews with the MLWs was to explore their current roles and practice and areas or training, which they perceived could support them to provide improved diabetes support and care to the ethnic minority people with diabetes and to obtain their views of the skills and experiences that would be required of a specialist

diabetes MLW. The main finding that emerged from this process was their perception that their roles were mainly limited to liaison and interpretation. Although they also reported delivering basic training to the patients around the use of their blood glucose systems and empowering them, they mostly acted as intermediaries between these patients and their healthcare professionals, that is, taking information from patients to healthcare professionals regarding their care and vice versa. They felt that a level of diabetes specialist training (such as for NVQ level 3 support worker) would instil them with adequate knowledge to empower ethnic minority patients to self-manage their diabetes. For example, one participant illustrated:

“I mean it [specialist training]’ would be good. Obviously by working with them [diabetes specialist nurses] for such a long time, I usually have a joke with them because I know I’ve planned that this insulin needs to go up and that needs to go down, sort of thing... the specialist nurse is going to change it, but having that extra training and knowledge ,say NVQ level 3, would be very useful for me because it would cut off quite a lot of the time that you’re spending asking the nurses or the doctors or seeing the patient and then waiting for someone to actually action the care they need, yes” [MLW 2, one-to-one interview].

Further findings from the MLW interviews are also synthesised within the main themes (Section II), which emerged from the overall PR.

6.5.3. Synthesis on of the results based on emerging themes

Section I presented the chronology of the research with some illustrations of what happened during each of the three research methods used in the PR process. In this section, findings from all these methods are combined. The six main themes and subthemes that emerged (see Table 6.4) are: need for the service (cultural barriers), training and education, functions of MLW, information sharing, partnership working, and service commissioning.

Table 6.4: Themes and subthemes

1. Need for the MLW service (cultural barriers)	2. Training and education	3. Functions of DSMLW	4. Information sharing	5. Partnership working	6. Service commissioning and challenges
(a) Cultural barriers	(a) Training of practice staff	(a) Patient referral pathway of DSMLW service	(a) Professional information sharing between DSMLW and staff	(a) Working relationship within the practice	(a) Sustainability and financial implications (managing present and future diabetes service provision)
(b) Low health literacy level	(b) Training of MLW and level of specialist knowledge (training of trainee)	(b) Responsibilities of DSMLW	(b) Information sharing with the patient by DSMLW	(b) Working relationship with partner agencies (establishing collaborative relationships between local practice and partner agencies)	(b) Engaging and sharing good practice.
(c) Language barrier (problems associated with family members as interpreters)	(c) Trainee-patient training	(c) diabetes self-help groups	(c) Education sessions/clinical consultations		
(d) commitment to religion	(d) Supervision and monitoring training				

6.5.3.1. Need for the MLW service (cultural barriers)

During the first two weeks of participant observations, the general practice staff reported cultural barriers around language differences between patients and themselves, religious beliefs, low health literacy low and non-concordance with medication and dietary advice, as issues affecting diabetes primary care service provision to ethnic minority patients within their practice. These issues were eminent as witnessed by the researcher and found to compromise the level of diabetes care received by ethnic minority patients, which supported work reported in previous chapters. During PR meeting 1, practice staff listed and pondered on the six culturally-competent diabetes services (see Table 6.3) they perceived will lead to better diabetes delivery within their general practice and Coventry as a whole. The participant who initially proposed the MLW service as a priority said:

“I think it will really be useful for the practice if we have someone who is not a relative, like part of the team, helping our patients with language barriers during their appointments, and tell them exactly what we are saying, teach them about their diabetes too, maybe like a link worker,...yes, multilingual link worker” [HCP 1, PR meeting 1].

The other participants responded:

“Yea, yes...” [All, PR meeting 1].

6.5.3.1.1. Cultural differences/barriers

At PR meetings, especially meeting 1, participants reported that ethnic minority patients have more issues around managing their diabetes and this was noticed during participant observations that some ethnic minority patients needed more time with healthcare professionals and had to be reassured on any advice given to them. An argument for a link worker was reinforced:

“Explaining diabetes management to them [ethnic minority patients] is very difficult because their diet is different as well and the culture and every other thing, and they don’t understand most of the things that we [healthcare professionals] are saying. I think there is a role for the Link Worker here to help, especially when they see the nurse”[HCP 1, PR meeting 1].

Another cultural difference was witnessed with a 41 year old South Asian lady, with type 2 diabetes on tablets and insulin, overweight, with a big family and non-concordant with medication and dietary advice (reported not taking her prescribed diabetic tablets but only takes insulin and not as prescribed). This patient’s diabetes was not well controlled (evidence from her diary and HbA1C results). The patient had been referred to dietitian three times but did not attend any of the appointments. The patient reported that the reasons for not taking the tablets were because they weakened her and made her sleepy, making her unable to care for her children. When asked by the researcher during consultation, how she would like to manage her diabetes, the patient responded:

“My diabetes is well controlled...each time I go back home [Pakistan], my diabetes is good and I don’t have to take all the medications, I feel strong but here, I always feel sleepy and weak, so, I don’t take tablets” [South Asian Patient, Participant observation field notes].

On exploring the issue with the GP after the consultation, it was confirmed that the patient was in self-denial of diabetes for months, but thinks it’s the British weather that causes diabetes. When this aspect of culture was further explored during participant one-to-one interviews, the responses were mainly associated with mistrust and cultural norms that Western medicines had detrimental effects and some ethnic minority patients preferred to take complementary therapies. One staff participant explained:

“To their appointments and even they [minority patients with diabetes] reported they were also using the herbs when they were going back home [India]. They were not using the insulin or the tablets from their GPs. They were thinking because now

they're sweating more, they don't need to take the medication" [MLW 1, One-to-one interview].

In addition, participants reported that cultural beliefs were factors contributing to patients not being proactive in terms of diabetes self-management, which could have a negative impact on their diabetes treatment:

"There are a lot of cultural barriers with the understanding of diabetes and with the understanding of the illness and the medication, especially in South Asian and Afro-Caribbean people...this makes it more difficult because of the cultural beliefs as well, so sometimes that can be a big hindrance to initiate treatment, or to make them understand about diabetes..." [HCP 1, PR meeting 2].

However, one participant felt perhaps changes to cultural practice need to be gradual and subtle and healthcare professionals should be sensitive to some issues:

"Well, if you look at some of the Asian cultures... you have to remember the way they [South Asians] feed their families at home. They do huge dishes for everybody, so if they're going to change the way they make a meal for themselves, then that will impact on everybody, because they can't be doing different meals for everybody, so it's making small subtle changes that aren't going to affect the rest of the family, or get the family upset and sometimes it's maybe even doing it gradually. For example, the amount of oil that you put into a curry, you know" [HCP 2, One-to-one interview].

To effect this change, may require partnership working between healthcare professionals and the patients with their family members, the same participant continued:

"It might be that sometimes with Asian members you get a wife in, if it's a husband or a husband in if it's a wife...so that they can understand the information that you're giving and the changes that their family member will need to make, because it will impact on the whole family. You have to do that gradually because it does affect the taste. You can't say, "Right, from now on you can only do this." You have to be sensitive to the way people live, and again, things like a lot of Asian families will make a huge pot of tea with everything in it and they use things like evaporated milk, rather than skimmed or semi-skimmed, so it's little by little that change can happen and with family members helping out as well" [HCP 2, One-to-one interview].

During participant observations, this investigator had explored a similar story with a South Asian male patient, who had reported that because his wife does all the

cooking, any meal served on the table, he would eat. However, as a patient with diabetes, he tried to eat more fruit in between his meals.

6.5.3.1.2. Low health literacy level

Practice staff reported during the participant observations that the location of the practice was in one of the most deprived areas in the city, with high health inequalities around diabetes provision, many of their patients lacked understanding about diabetes and its related complications. Some of their patients cannot read their own language and breaking down information to their level of understanding is often difficult, complicated and time-consuming. However, during the PR meeting 1, staff had reported that they needed diabetes leaflets and audio/video cassettes in the patients' own languages. When further explored at this meeting, their reported patients' low health literacy levels, staff felt those patients with good health literacy skills will benefit from such and those who cannot understand may have assistance from family members or a MLW, if such information was available.

One participant who strongly believed that structured group education programmes will improve low health literacy level, lead to better diabetes self-management and empower patients to understand their diabetes and related complications said:

“some [ethnic minority patients] ideas in their minds which they had carried, like myths in their minds and they carry on with those myths and those myths need to be broken in a sense, or educated in a sense that they understand it logically to help them manage their diabetes” [MLW 1, One-to-interview].

Another participant further emphasised the difficulties encountered when not communicating or educating to patients' level of understanding:

“Oh people [patients] are whinging,” or whatever, but unless you have regular communication to their level, it can never been effective and you need

communication to be able to pass information backwards and forwards. You can't expect people to do something if they don't know about it and that's part of our job in healthcare, which is to communicate, is to teach, is to enlighten and is to give people the information so that they can make the appropriate and informed choices" [HCP 2, One-to-one interview].

6.5.3.1.3. Language barriers (problems associated with family members as interpreters)

Throughout participant observations and PR meetings, the ethnic languages (Table 6.5) were reported as the languages commonly spoken by patients within the practice. These languages were spoken by more than 50% of the patients. The practice manager during one of the PR meetings was nominated to provide the number of patients speaking each of these languages as their first language and not able to communicate in English but gave estimates rather than exact numbers. According to the practice manager, the highest were those patients who spoke Punjabi, followed by Polish.

Table 6.5: Language spoken by patients within the general practice

<ul style="list-style-type: none"> • Punjabi • Hindi • Gujarati • Urdu • Bengali 	<ul style="list-style-type: none"> • Mandarin • Polish • Farsi • Dari • Turkish 	<ul style="list-style-type: none"> • Somali • French • Russian • Kurdish • Czech
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Staff participants reported that formal (professional) and informal (family members or friends) interpreters were used when there is a language barrier between the patients and healthcare professionals. For example one participant said:

"...a lot of them [ethnic minority patients] that come in that can't speak English, if they have a phone they will call somebody while they are here [general practice] that actually speaks their language so they interpret whilst you are having a conversation, other come with them and at times we book an interpreter [professional] when we know they are coming to see a doctor or nurse. The interpreter speaks to them and tells them what you are trying to say" [Admin staff 2, PR meeting 2].

However, it was observed in practice that there were times when neither an informal or professional interpretation facility was available, which were unhelpful practices as they often led to wasted appointment time or unsafe consultation and prescription of care as illustrated in the aforementioned quotation from Admin staff 1. In fact, the debates over using 'informal interpreters' in health care settings cast doubt over the quality of the interpreted information and was confirmed during participant observations and PR meetings and strongly discouraged by most participants. For example, one participant said:

"My mum has diabetes and she doesn't speak English, you know, when I bring her to the doctor or nurse and they say something that may not go well with her, I just say tell her that they are saying exactly what I've been telling you, you know she has high blood pressure, anything bad will make it very high, so I know my mum...yes" [Patient 1, PR meeting 2].

When challenged by another patient participant, seconded by this investigator what this misinterpretation could mean for the mother if she became aware, the participant continued:

"Sometimes I do. Sometimes I do. Why? For her own benefit, what it is, is that some patients who have got this [high blood pressure], if you tell them all the information they'll stress out and because of stressing out they increase their blood pressure, the diabetes and everything, so because of their own benefit we have to sometimes hide things" [Patient 1, PR meeting 2].

This misinterpretation was also confirmed by a staff participant and witnessed by this investigator during participant observation. In one scenario, the healthcare professional was explaining blood test result to an 83 year old South Asian patient with type 2 diabetes, via the patient's daughter. However, the daughter was interpreting or translating in one word or very short sentences, when asked to fully explain the information to the father, her response was:

"I know what he [father] wants to hear and anything else will just make things difficult for me." [Participant observation field notes].

Therefore, all staff felt that should a MLW be implemented it will resolve some of language challenges and other issues around clerical staff not respecting professional decisions, perhaps due to due to financial cost to the practice. For instance, when asked how easily it is to get a professional interpreter, one staff participant replied:

“Not always easy and there’re times, I request and it’s rejected...I know I can take one lady who is an Asian lady and she doesn’t – she has very limited English. She doesn’t understand what I’m trying to tell her. We do have a problem with her diabetes. I asked reception staff to book an interpreter who speaks her language and I was told, “Well she’s got a son that speaks English,” and I said, “Yes but she’s already told me he can’t come. He’s working. Please book me an interpreter,” and what happened was they phoned the family and told them somebody had got to come in with her, so they sent in a 12 year old boy as interpreter, who didn’t understand what I was telling him. He couldn’t pass on – no, he was trying his best, God love him, to pass on the information I was giving, but he didn’t know what I was saying to him. He didn’t understand it” [HCP 2, One-to-one interview].

When asked how they felt about the incident, HCP 1 continued:

“I was cross and I did tell them off at the reception and I said, ‘When I ask for an interpreter, I want an interpreter. I don’t want a 12 year old, because you’ve put that child in a difficult position and you’ve put the patient in a difficult position. You’re wasting everybody’s time.’ The child lost time from school... it’s very frustrating, you know, it’s even more frustrating for my poor patients.”

The situation where very young children interpreted for their parents was also witnessed during participant observation where a thirteen year old boy accompanied his father who (who spoke very little English) needed holiday vaccines to travel to Pakistan. However, this case was easily understood by the GP, who asked the nurse to administer the appropriate vaccines. The boy reported that he had to leave school earlier in order to accompany his father to the general practice.

Stating their experiences and why they dislike family interpreters, one staff participant replied:

“I’m not always a hundred percent sure that they give accurate information. In fact I know that they don’t sometimes, or that when I’m asking a question of a patient, be it their family member, they will give me the answer and don’t ask the patient and I will insist, “Can you ask your mum or dad? Ask your mum please.” “Well, I know she does this.” “Yes, I’m sure you do, but can you please just ask your mum? I need to see her answering, yes, and then you tell me what she says exactly, and it might be that it isn’t appropriate to have a family member as an interpreter. It may be that you want an external person to come in and interpret for you, for the sake of your patient, because it’s not always good to have a family member. You don’t always want family members knowing everything do you? Personal stuff, for example, if someone has erectile dysfunction because of diabetes, they might not want to discuss that via a daughter or a son or in the case of a lady, if you’ve got to talk about her weight. Again, she might not want a family member talking about that, or if you’ve got to talk about periods or menopause or anything like that, so there are sensitive issues that you need to be aware of” [HCP 2, One-to-one interview].

Although some of these sensitivities had been expressed by most participants during PR meeting 1, another staff participant re-echoed HCP 2’s experience:

“Sometimes relatives do act as interpreters, which might again affect the amount of information passed onto the patient as well, so multilingual link workers would be better.” [HCP 1, One-to-one interview].

6.5.3.1.4. Commitment to religion

During the three research methods used in this study, staff reported that it is usually a challenging period prior to Ramadan, as the practice has a high population of Muslim patients who fast during this period. An example of commitment to religion witnessed by this investigator is reported in section I above (chronology of the research under participant observation) where a Muslim patient whose diabetes was not well controlled wanted to fast during Ramadan. Other religious commitments were also reported by participants. For instance, one participant said:

“Things like insulin therapies might have an implication. For example, you have to make sure that you’re using the right kind of insulin for different cultures. They [Muslim patients] might object to some rather than others, and looking at the makeup of some of the drugs as well; making sure that they don’t have things like gelatine in them if you’re treating Muslims and things like that, so it’s got further implications, especially with their religion” [HCP 2, One-to-one interview].

Due to religious beliefs some patients may also prefer certain food, and other participants stressed the importance of healthcare professional taking into account the cultural background of patients with diabetes and the types of food they eat as illustrated below:

“It is very important to understand their religious beliefs, their food types, what they eat and everything, so I think it is very important to know the background of the culture to effect care” [HCP 1, PR meeting 1].

All the other three participants present at this meeting concurred with HCP 1 by a head shake.

6.5.3.2. Training and education

The findings of this study suggest that the cultural barriers reported by practice staff as impeding their ethnic minority patients from accessing effective diabetes care, coupled with lack of appropriate culturally-competent staff within the practice, led participants to report the need for a culturally-linguistically-competent multilingual link worker. According to the participants, the link worker should possess a level of diabetes knowledge and skills in order to support and signpost diabetes services to minority patients within the practice and partner agencies. All staff participants reported that they had never received any formal culturally-competent training and their experience was based on their daily encounters with ethnic minority patients with diabetes. They felt that additional culturally-competent training of primary healthcare professionals would lead to better relationships with their ethnic minority patients, and prepare them to tailor individualised diabetes care based on cultural differences with the overall aim of improving patients’ diabetes related outcomes, including biomedical outcomes (e.g. HbA1C, BP, lipids) and patient self-reported quality of life. For example one participant said:

“Culturally-competent training? I definitely do. I definitely do it would improve care, because if you don’t understand a client then how can you give them the right information and the right help? You’ve got to be able to understand them and understand their backgrounds and where they’re coming from and their cultural needs to be able to give them the right advice and information because you can tell them whatever you want, but if it doesn’t fit in with their personal needs and requirements, they’re not going to do it, so it must help” [HCP 2, one-to-one interview].

Another participant also had a similar opinion:

“...I think it’s all about training, isn’t it? If the doctor or nurse understands the patient’s culture and their language, it can make a big difference, yes?” [Patient 2, PR meeting 3].

6.5.3.2.1. Training of practice staff

All four practice staff participants reported that they receive mandatory training and other training to support their professional roles as identified at appraisal, with most of the training provided by NHS Coventry via Protected Learning Time (PLT) and other agencies such as pharmaceutical companies and academic institutions. However, they reported receiving limited culturally-competent training as explained by one participant:

“Yes, well in training I think there was a project which was done by UKADS, which was looking specifically at South Asians and treating diabetes in South Asians and I found that very good, because they were able to understand south Asians’ culture better and make them understand about the condition better and treatment as well using specific interpreters with the South Asian language. That was a good one provided by Diabetes UK...but with my practice, no we don’t have it [culturally-competent training] in the practice, any culture competency training would be good...” [HCP 1, One-to-one interview].

All staff participants felt that culturally-competent training will improve relationships between patients and staff and lead to better diabetes care of minority patients within the practice. However, one admin staff slightly differed and felt this training was only useful to frontline clinical staff as elucidated:

“I think it would be important for clinicians to have this training [culturally-competent training]. I’m not so sure about admin staff because what you’ve got to be careful of

is as in the fact that it's... Yes, it's not up to the admin staff to be managing our patients. Our admin staff really shouldn't be giving patients advice over diet and so forth because they don't know enough about the patient to be in that position. I think it wouldn't hurt for our clinical staff to attend sessions on cultural differences so that they have knowledge of maybe the reasons behind why patients don't attend appointments at certain times of the year, or why patients find it difficult to manage their disease" [Admin staff 1, One-to-one interview].

6.5.3.2.2. Training of MLW and level of specialist knowledge (training of trainee)

During PR group meetings all participants reported that as there was a low level of culturally-competent diabetes services with the practice, the MLW would require specific skills and knowledge from both the general practice (Table 6.6) and external agencies (Table 6.7). These issues were reiterated during one-to-one interviews. For example one participant put his point through, which was generally supported by other participants:

"...not just giving informal teaching [by practice staff] is not going to give enough information for the Link Worker. So having proper specialist training might be better. It will still help having some sort of informal teaching as well within the practice because it is important for the Link Worker to understand how each surgery works, how the practice works, what are the roles of each individual [staff] within the practice, so in that way that would be good as well, but getting both formal and informal would be a good option" [HCP 1: PR meeting 4].

Another participant also talked of the usefulness of the internal training for the link worker:

"We would be quite happy to have a potential Link Worker sitting on diabetic management with the practice nurse so they would get first-hand knowledge of what the practice nurse does, as in examining feet and going through diet, talking about medications, blood pressure, even sitting in with the GP with a diabetic patient, so they get that first-hand knowledge" [Admin staff 1, PR 4].

Therefore, participants in the PR meetings including the two MLWs proposed skills which have been summarised (Table 6.8) as a requirement to make the MLW attain a specialist level from internal and external training media. All participants felt it

would be important for the MLW to acquire specialist knowledge to a certain level in order to effectively support these patients as one staff participant explained:

“Well, what I think we need to be looking at is what specialist knowledge and level we want the Link Worker to actually have” [Admin staff 1, PR meeting 4].

The other participants responded:

“Yeah” [All other participants at PR meeting 4].

Further illustrations are expressed by other participants. For example, one participant commented:

“Here in the hospital, we have the Diabetes Alphabet Strategy, I think it will be useful for this multilingual worker to get this specialist from it, because it will help them and enable them to know what to tell the patients about their diabetes” [MLW 2, One-to-one interview].

The need for specialist training and level of skills was echoed by another participant:

“Some of the tutors who deliver the EPP are not clinical staff but because it [EPP course] is a prescriptive programme, once they [EPP tutors] have gone through the training and develop the confidence, they deliver it very well to patients, ...so link worker who doesn't have a clinical background can learn the skills needed for the job and deliver it to the patients” [MLW 1, One-to-one interview].

Table 6.6: Recommended in-house training and skills for DSMLW

- | |
|---|
| <ul style="list-style-type: none">• Induction programme period to learn from all staff groups the operational activities of the general practice. This should include tours to various clinical and non-clinical areas within the general practice and partner practices as well as attending the required health and safety and other mandatory training• Get accustomed to routine activities within the practice, such as patient journey, seeing a patient with the doctor or nurse, and etc• Interpreting and liaising with patients and staff due to language and cultural differences• Directly provide some aspects of care and treatment in support of programmes of therapy and intervention supervised by nurse or GP• Completion of compulsory shadowing activities in various staff roles. |
|---|

DSMLW (Diabetes Specialist Multilingual Link Worker)

Table 6.7: Recommended external training and skills for DSMLW

- Diabetes course from a pharmaceutical or academic institutions
- Diabetes training from Diabetes Specialist nurses, dietitian and GP with special interest in diabetes in blood glucose monitoring and use of glucose meter, weight management, dietary advice (knowing food from different ethnic backgrounds) and exercise, blood pressure, foot care
- Training on how to use audio or video recordings with patients who cannot read or write in their own language.

Table 6.8: Recommended specialist skills and training of DS MLW

- Attend Warwick University diabetes certificate course to be confident in discussing diabetes issues and related complications with patients, such as effects of diabetes in the body, HbA1C, blood pressure, weight management, dietary issues (such as nutrition, ethnic foods and cooking style) and diabetes related complications, such as kidney and other organ damage
- Be competent in the use of Diabetes Alphabet Strategy
- Accredited course in structured diabetes education programmes, such as DESMOND or similar, which they can then organise and deliver patient group education in diabetes (structured or unstructured) in mixed or separate ethnic groups
- Medical interpretation training programmes
- Able to train lay people to deliver DESMOND courses to different groups of EMGs and act as mentors until they become competent*
- Culturally-competent training tailored to individual needs of ethnic minority patients with diabetes.

*** This would require accreditation as a DESMOND trainer.**

6.5.3.2.3. Trainee-patient training

Participants at both PR group meetings and one-to-one interviews reported that should the DSMLW acquired the above skills (Tables 6.6, 6.7 and 6.8), they would be able to cascade this training, support the practice and empower ethnic minority patients to self-manage their diabetes. The support could include making home visits for home-bound patients as explained by one participant:

“If they [MLWs] receive all this training, they will help the patients with diabetes, and this will be good, yes, they can train the patient and family members to help with the insulin and glucose reading...” [MLW 1, One-to-one interview].

Another participant had expressed potential benefits of having a link worker rather than interpreters:

“...I think the Link Worker will be more reliable than family members or interpreters because they will know the patients and the information to pass onto them and these patients will develop interpersonal relationship with the Link Workers and always have a contact point to refer back to, should they have any issues with their diabetes” [HCP1, PR meeting 4].

6.5.3.2.4. Supervision and monitoring training

At PR meetings and interview sessions, most participants felt that both the volunteers and paid MLWs would require supervision to ensure that they have adequate support and counselling when faced with challenging situations and the ethnic minority patients when newly diagnosed with diabetes or started on insulin. One participant explained:

“It will not be very easy for the link worker but I think with all the training and support from the diabetes specialist nurses, they can really help the patients, the GP too can help the link worker...” [MLW 2, One-to-one interview].

In making sure those with language barriers were closely followed-up, another participant commented:

“I used to make home visits to see the patients and help them, so it shouldn't be different, once they [minority patients] have seen the nurse or doctor and everything has been explained, the link worker can continue to help the patients with follow-ups, asking for their readings and checking if they are taking their medication” [MLW 1, One-to-one interview].

6.5.3.3. Functions of DSMLW

Based on cultural barriers reported above, participants explored specific functions of the DSMLWs during the PR meetings to help improve diabetes service uptake for ethnic minority patients within their practice and their relationships with practice staff as well as service utilisation.

6.5.3.3.1. Patient referral pathway of DSMLW service

To ensure the service was appropriately utilised, ideas were shared at group and one-to-one meetings, and the pathway below (Figure 6.1) was formulated during PR meeting 3 and tentatively adopted at PR meeting 5. For instance, when asked at one PR meeting who is responsible for assessing the cultural and language needs of the patients, one patient participant said:

“I think when the patient comes for their appointment, the staff at the reception would know if the patient can understand English and things like that... Then, the doctors or the nurse will know more about the patient and whether they need a link worker or not” [Patient 1, PR meeting 3].

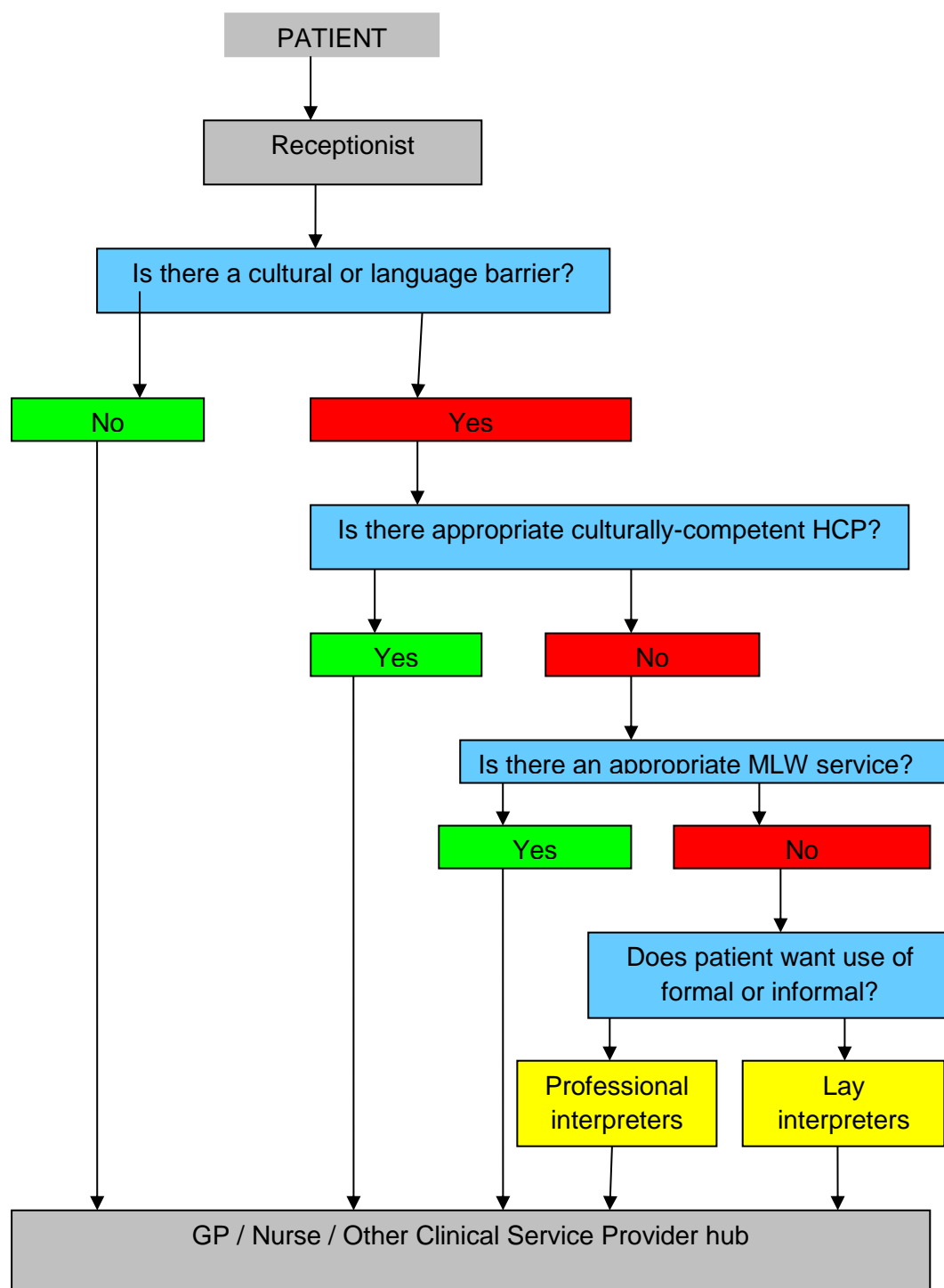
It was not until at the one-to-one interviews, that it became much clearer that most participants felt that the assessment for the need of a multilingual link worker should start from when the patient first registers with the general practice. One participant gave a sequence of the pathway:

“The receptionist books the interpreter when the patient can’t speak English, they [receptionists] know most of the patients and will know who needs a link worker, but it will depend what languages our link worker can speak,...perhaps interpreters or relatives might still be needed in some cases, but link worker is better” [HCP 1, One-to-one interview].

It was acknowledged that DSMLWs will not be available in all practice’s registered ethnic minority patients’ languages. Therefore, room should be allowed for occasional use of professional interpreters and informal interpreters, such as family members or friends within the pathway. One participant explained:

“It may mean we have to review all our patients and see those that have language problems and find out if they need a link worker or their family members to be there when they attend their consultation” [Admin staff 1, PR meeting 5].

Figure 6.1: Flow diagram for the proposed Diabetes Specialist Multilingual Link Worker framework model (based on PR meeting group discussions and one-to-one-face interviews)



6.5.3.3.2. Responsibilities of DSMLW

The job description (Table 6.9) was formulated by this researcher using an earlier version proposed by participants at PR meetings (Appendix 20), a generic job description for a multilingual co-worker (Appendix 21), which was provided to participants by the researcher at PR meeting 4, and by participants' views during the group meetings and the one-to-one-face interviews. During PR meeting 5, the researcher was assigned by participants to review all completed meeting data, and revise the earlier proposed version and forward to participants. This job description (Table 6.9) was formulated after the initial data analyses and forwarded to all PR participants two months after all the one-to-one-face interviews had ended, along with the validation letter/form (Appendix 22). All six participants returned their completed form within four weeks, with all of them selecting option (1) which stated: *'I am completely happy with the content'* of the proposed job description. Furthermore, additional individual contributions to the job description are illustrated in subsequent themes and sub-themes below. The section on the job description 'Freedom to act', 'Physical effort', 'Mental effort', 'Emotional effect', and 'Working conditions' are adopted from generic job descriptions of a similar role. Therefore, this document (Table 6.9) has been validated and adopted by all PR group meeting participants. This job description provides the detailed functions of the role of a DSMLW.

Table 6.9: Diabetes Specialist Multilingual Link Worker Job Description**Post Title:****Diabetes Specialist Multilingual Link Worker****Band:**

4

Post Ref. No.

1. Job Details	
Job Title :	Diabetes Specialist MLW
Service :	NHS Coventry
Department/Directorate	General Practice
Reports to (Title):	Practice Manager
Accountable to (Title):	Lead General Practitioner
Location/Site/Base:	Coventry North

2. Job purpose/main duties/responsibilities

To lead the work of Diabetes Specialist MLW model within the practice, developing and maintaining positive working relationship with patients and practice staff as well as partner agencies. To assist healthcare professionals in appropriate roles within the practices and visiting ethnic minority patients in their homes or appropriate settings or contacting them by phone in appropriate languages. To support clients when accessing services at practice and signposting other community diabetes services by providing guidance and interpretation. To promote and inform on equality issues throughout the general practice and Coventry community. To signpost DSMLW model and support the ethnic minority patients in the practice and work towards their action plan as directed by clinical healthcare professionals. To undertake prescriptive tailored diabetes patient education in appropriate languages, such as DESMOND or one-to-one and ensure the education is delivered to agreed standards and regular monitoring is conducted.

3. Key Responsibilities/Duties

1.	To be part of the practice staff and develop and maintain a register within the practice VISION database containing ethnic minority patients with diabetes having cultural and language differences.
2.	To promote awareness of MLW model within practice staff in additional to partner agencies and signpost the MLW model to support ethnic minority patients registered with the practice and work towards their action plan as directed by clinical healthcare professionals.
3.	To educate and encourage the ethnic minority patients to take ownership of their diabetes action plan.
4.	To arrange meetings and signpost community diabetes services to EMGs and support these networks (e.g. contacting service leads on behalf of the patients, and getting feedback on the use of these services, etc.).
5.	Work positively in partnership with practice staff and partners and maintain regular contact with the Direct Line Manager and multidisciplinary healthcare team in order to debrief, discuss issues and share relevant information that

	may affect patient care due to their cultural backgrounds.
6.	To keep clear and comprehensive records of work undertaken in accordance with local general practice and NHS Coventry record keeping protocol.
7.	To work with practice staff and other Diabetes Specialist MLWs to ensure all patient education materials are accessible to patients with diabetes whose first English is not English and to patients who do not read in their own first language.
8.	Work effectively with the community diabetes specialist nurse and dietetic teams and ensure ethnic minority patients with complex diabetes needs are appropriately referred into the teams and supported in their appropriate language.
9.	To provide interpreting to a professional standard for staff, patients, their relatives and carers and to work alongside professional interpreters, where appropriate.
10.	Devise flexible ways of working and be prepared to provide emergency interpreting at short notice referring patients to other agencies where appropriate.
11.	To liaise with and support families and carers of patients to maximise understanding of particular conditions and health care being offered.
12.	To directly provide some aspects of patient care and treatment in support of programmes of therapy and intervention under the instruction or supervision of qualified healthcare staff.
13.	To deliver prescriptive patient education programmes such as DESMOMD course programme to different groups of EMGs and ensure the patients are monitored and continuously supported.
14.	Liaise with local statutory and voluntary organisations on the shared agenda for improving race relations and reducing inequalities, and organise events, with the agreement of the Practice Manager and Lead GP, to ensure that the profile of Diabetes Specialist MLW role and race equality work is positive in both practice and related agencies and that it contributes to the larger equalities agenda.
15.	Be non-judgmental and respect every individual's spirituality on its own terms, including those that do not have a religious connection.
16.	Maintain confidentiality and ensure patients and other members of the public data are kept in accordance with Data Protection Act.
17.	Develop and deliver appropriate diabetes awareness raising activity (e.g. workshops, and training sessions) in relation to the promotion of MLW model and evidence-based practice.
18.	To prepare quarterly and adhoc monthly annual reports relating to MLW service utilisation and clinical adverse events.
19.	To be proactive towards research and, Patient and Public Involvement clinical audit activities and develop good links with the ethnic minority communities.
20.	To support the development and implementation of strategies and policies related to the MLW model effectiveness.

4. Responsibilities of the Post Holder for Corporate and Specific Areas

1.	To contribute to the development of the general practice policy and procedures and take responsibility for directing own learning.
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2.	To comply with the NHS Code of Conduct and any other Professional Code of Conduct relevant to the post.
3.	To follow and adhere to the Local Health and Safety Policies and instructions and be responsible for own and others health and safety in the work place.
4.	To adhere to the legal requirements of the Sex Discrimination Act 1975 (as amended) Race Relations Act 1976 (as amended), the Disabled Persons (Employment) Act 1994 and 1998, the Disability Discrimination Act 1995 and all other Equalities legislation as it is enacted.
5.	Be committed to the principles of diversity and equality.
6.	To provide benchmarking information to operational MLW services as required.

5. Freedom to Act

Manage own workload with minimal supervision.

- Organise and supervise ethnic minority patients' with some aspects of their patient care and treatment in support of programmes of therapy and intervention under the supervision of qualified healthcare staff.
- Prioritise MLW model requests based on needs and in line with local and partner agencies requirements.
- Coordinate liaison and interpretation with internal and external contacts ethnic minority patients' needs with minimal supervision.
- To contribute to the development of the general practice policy and procedures and take responsibility for directing own learning.

6. Physical Effort

- Daily use of computer and keyboard for data inputting and occasional running of reports
- Regular requirement to drive to other locations across Coventry and other appropriate locations.
- May be required to carry materials for patient education training.

7. Mental Effort

- Dealing with patients with cultural and linguistic barriers will be challenging and requiring interpersonal communication skills and escalating unresolved urgent matters immediately to appropriate personnel.
- The work pattern is unpredictable and includes direct exposure to personal, difficult, distressing or emotional circumstances.
- Delivering objectives within a resource-limited environment.

8. Emotional Effect

Working with patients with diabetes and other chronic conditions will require post holder to deal with emotional distress occasionally.

9. Working Conditions

This role is general practice based but may also require remote working and travel as

a routine way of working.

The job description is an outline only and may be amended in detail and/or emphasis from time to time, to take account of any changes following discussion with the Post Holder.

Job Description Agreement

Job Title: Diabetes Specialist MLW

I declare that I have read the Job Description and Person Specification and confirm that this is an accurate and fair description of the role.

Signature:

Date:

Job Holder:

Name:

Line Manager:

Name:

PERSON SPECIFICATION

JOB TITLE: Diabetes Specialist Multilingual Link Worker Band 4
DEPARTMENT: General Practice

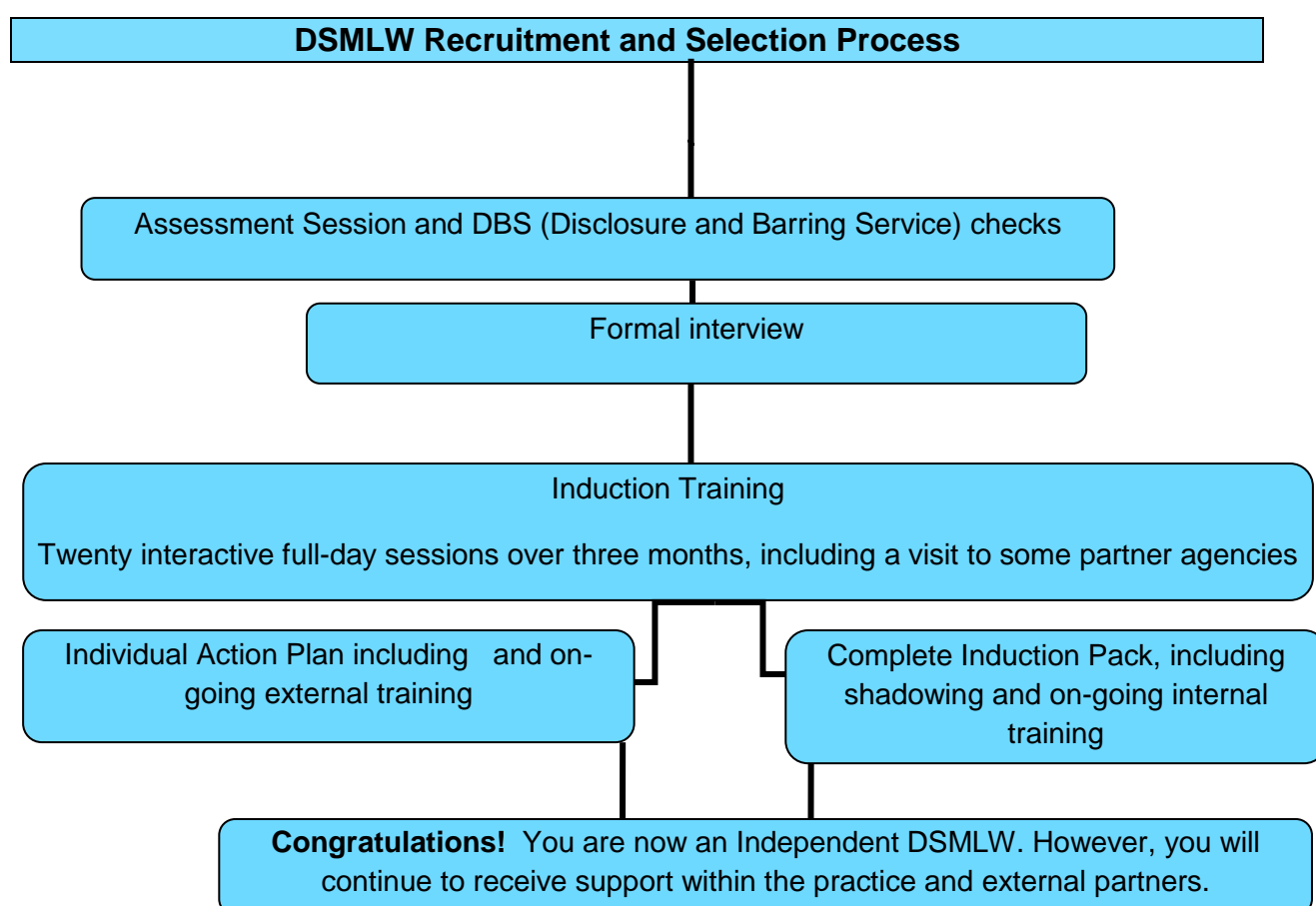
	ESSENTIAL JOB REQUIREMENTS	DESIRABLE JOB REQUIREMENTS	HOW IDENTIFIED
Qualification/Training Level of education Professional qualifications / Vocational training / Post basic qualifications / Training and learning	<ul style="list-style-type: none"> Two years' experience in a relevant specialty at Band 4 or equivalent Educated to NVQ Level 3 or diploma level (or its equivalent) or above or willingness to undertake A language 	<ul style="list-style-type: none"> Professional qualification in any health related field or willingness to undertake any health related professional course 	C/I

programme courses	qualification relevant to the local population from GCSE level onward <ul style="list-style-type: none"> Evidence of continuous professional development 	<ul style="list-style-type: none"> Teaching and assessing qualification 	
Experience Type of experience	<ul style="list-style-type: none"> Experience of working with multi-ethnic communities with diabetes or other chronic conditions Be committed to the multi-faith ethos of NHS or other organisations Experience of coaching and empowering patients with diabetes or other chronic conditions Experience of communicating both orally and in writing in more than one language including English Experience of working with different staff groups 	<ul style="list-style-type: none"> Experience of delivering self-management courses to patients with diabetes or other chronic conditions Experience and understanding of diabetes primary care service provision in primary care Experience of presenting and speaking at training and local events 	AF/I
Knowledge Specify any specialist (depth and extent of) knowledge required	<ul style="list-style-type: none"> A culturally-competent and knowledgeable individual with the ability to apply evidence based practice Awareness and understanding of current key issues within the NHS and general practices A Knowledge of MLW model framework in clinical practice 	<ul style="list-style-type: none"> A good understanding of current issues relating to the NHS. Knowledge of research, clinical audits and PPI activities involving patients 	• I
Skills & Abilities	<ul style="list-style-type: none"> IT skills 	<ul style="list-style-type: none"> Excellent 	

<p>Responsibilities (specify the extent of responsibility for resources and physical assets) Management/supervision/ coordination skills (specify level)</p> <p>Verbal/Written communication (specify extent, frequency, level and types of communication required to use/)</p> <p>Physical skills</p>	<ul style="list-style-type: none"> • Patient focused • Excellent communication and negotiation skills • Able to prioritise and meet deadlines effectively • Good management of own time • Able to use initiative and make decisions • Motivated and able to motivate and empower patients and others • Ability to work on own initiative and as part of a team • Ability to manage emotional distress and complex relationships • Professional at all times • Good organisational skills • Car owner/driver and able to travel across Coventry and other location as required. 	<p>presentation skills</p> <ul style="list-style-type: none"> • Analyses problems and implements effective and appropriate solutions • Have a confident approach, and the ability to inspire confidence 	<ul style="list-style-type: none"> • AF/I
<p>Personal Qualities</p> <ul style="list-style-type: none"> • Specify attributes required • 	<ul style="list-style-type: none"> • Patient and good listener • Calm and objective • Approachable • Good interpersonal skills • Ability to establish and maintain effective working relationships at all levels of the general practice and with partner agencies. 		<ul style="list-style-type: none"> • AF/I
<p>Effort</p> <ul style="list-style-type: none"> • Emotional(specify the nature, frequency and duration required to deal with distressing or 	<ul style="list-style-type: none"> • Ability to deal with difficult/sensitive situations daily 		<ul style="list-style-type: none"> • AF/I

emotionally demanding duties			
Other job requirements <ul style="list-style-type: none"> Specific circumstances Special requirements 	<ul style="list-style-type: none"> Occupational Health Satisfactory attendance record CRB checks 		<ul style="list-style-type: none"> I/C

How identified: AF- Application Form; C - Check; I - Interview



6.5.3.3.3. Diabetes self-help groups

Participants shared views regarding lay people self-help groups involving people with diabetes. According to most participants, people with diabetes need information to help them understand and self-manage their diabetes. This information is sometimes delivered by people who have the same medical condition. Furthermore, some participants felt that the healthcare professionals and the DSMLW may not always be available for the patients, therefore, creating self-help groups of same ethnic minority people with diabetes may help them to share coping/managing strategies, which may help them to understand that what they are experiencing is not unique to themselves. For instance, one participant said:

“I go to this West Indian community group, and there some people there with diabetes, we talk about it [diabetes] and what the nurse or doctor said, and I always tell them the type of food I cook and how my diabetes is doing, and we talk about exercise and all sorts...” [Patient 3, PR meeting 5].

However, according to one participant, creating these self-help groups can actually be part of the DSMLW's role:

“When patients [minority patients] finish DESMOND, there still will need support and all sorts of things, encouragement and reassurance, the link worker can help...but not all the time, so they [DSMLWs] can create these groups and refer the patient there, like in the temple or mosque...” [MLW 1, One-to-one interview].

6.5.3.4. Information sharing

The data revealed that ethnic minority patients did not always receive appropriate and/or consistent information following diagnosis of diabetes and on-going care; sometimes healthcare professionals lacked the therapeutic communication skills required to relate to the already anxious patients. Participants shared their views on how this sharing of information between patients and healthcare professionals can

be complicated and miss-interpreted as well as information sharing amongst staff. These are illustrated within the sub-themes below.

6.5.3.4.1. Professional information sharing between DSMLW and staff

With regards to this subtheme, participants' views were generally that the procedure of handling and sharing patient information regarding their care with DSMLW and clinical staff would need to be clarified at induction period. This will ensure it is consistent and well understood by all the parties, that is, clinical staff, DSMLW and the patients. Participants also stressed the importance of the DSMLW consulting with the relevant clinical staff when they are unable to meet patients' needs. In particular, should the DSMLW implement group education sessions within the practice and/or make home visits in line with their responsibilities (see job description on Table 6.9 above). For example, one participant emphasised:

"There would need to be a proper format where the outcomes especially issues where the Diabetes Specialist Multilingual Link Worker could not resolve can be brought to the attention of the clinical staff" [Admin staff 1, PR meeting 4].

Another participant added:

"Clinical consultations could be organised to suit all the parties [DSMLW, clinical staff and patient," [HCP 2; One-to-one interview].

This was because effective diabetes self-management depends greatly on how and what information patients are given by their healthcare professionals, which must be consistent to ensure concordance.

6.5.3.4.2. Information sharing with patients by DSMLW

The data suggest that information sharing with minority patients by the DSMLW would need to be therapeutic, that is, the DSMLW should possess interpersonal

skills to ensure they effectively communicate with the patients in a culturally appropriate manner to enable concordance with the information regarding diabetes management. For example, one participant said:

“I think they [DSMLWs] should have very good personal skills first of all, because it is very important to develop a good relationship for them as well with the patients and it is very important that they are also very good in their communication skills and whatever language they are speaking, very fluent in their language and they understand a bit of medical terms...” [HCP 1, PR meeting 4].

Furthermore, participants discussed various means by which the DSMLW can effectively communicate with the ethnic minority patients with diabetes to alleviate cultural barriers. These included setting up a little library with appropriate patient information within the general practice, using pictorial, videos and audio-cassettes in patients’ appropriate languages. One participant explained:

“If there is a room within the practice with diabetes information in different languages and videos about diet and other things, the link worker can use with the patients or they [patient information] can be loaned out to patients and used at home with their families” [Admin staff 1, .PR meeting 4].

This view was generally supported by other PR meeting participants. Participants described the calibre of the DSMLW that will bring about therapeutic communication with minority patients, with one participant stating:

“... but you’d want somebody [DSMLW] that has good communication and language skills in English as well as in own their language, so generally it would be somebody that’s been well educated...have good interpersonal and communication skills, be a good listener, be well organised and resourceful” [Admin staff 1, PR meeting 4].

6.5.3.4.3. Education sessions/clinical consultations

All participants reported that the DSMLW will have responsibilities in helping minority patients with cultural barriers in structured or unstructured group or one-to-one education settings. It was also felt that the DSMLWs will participate during patients’ clinical consultations to interpret and/or simplify clinical information to them. To

effectively utilise the DSMLW service within the practice, all except one participant felt that elective consultations will be booked based on the availabilities of specific DSMLWs but also taking into consideration patients' willingness to keep the appointments. According to participants, this approach will save money and improve attendance rates, as these patients would be aware that they will be seeing someone who understands their language and culture and so get better support. For instance, one participant said:

"Obviously the advantage of being able to write and read the same language is that they [DSMLWs] can put down main factors on a piece of paper for the patient to take away with them, or if the patient is being referred on to another service, that, they can write where that service is and so forth and the patient then has actually got something physical to refer to" [Admin staff 1, PR meeting 5].

Another participant who was also in accordance with Admin staff 1 added:

"Interpreters are very expensive and sometimes you can't get them to do the job, so the link worker will be very good and will help the patients and the doctors and nurse, and can even see patients at home, so yes" [Patient 1, PR 5].

Two other participants agreed:

"Yes, yeah" [Patient 2 and Patient 3, PR meeting 5].

Relating to educating and helping patients to self-manage and overcoming the rhetoric especially of some Muslim patients of 'Allah gave me the diabetes and will look after me,' one participant cautioned and advised multidisciplinary team of healthcare professionals:

"Don't dismiss the patient by saying that patient is not complying. Look into other areas of why they're not complying...Yes, there's always...I mean there's always that thing about, you know, 'God wanted me to have diabetes, so he'll look after it for me,' but then God may look after – he will look after your diabetes, but I always tell them God needs you to do something as well, so you know, you have a responsibility, so he's put you on earth and he's given you the body and he's given you the organs. He's taken good care of you, but you will have to, you know – it's like we still have to eat, we still have to drink, so God provides for us, but we have to do that physically ourselves, so we have to make sure that our diabetes is looked after by us as well" [MLW 2, One-to-one interview].

6.5.3.5. Partnership working

The last two major themes which emerged from synthesising the results focused around partnership working and service commissioning. Discussions focused on how and whether the DSMLW can effectively work within the practice, and still be able to work with nearby general practices covering the needs of similar patient groups. This would ensure their practice benefits from the use of another DSMLW employed by partner practices, to provide culturally-competent diabetes services not offered by their service providers. Finally, it was felt by most participants that the need for the DSMLW service was fundamental but its implementation would be challenging, which would require careful planning to ensure adequate and long-term sustainability. Participants' voices are illustrated within the sub-themes below.

6.5.3.5.1. Working relationship within the general practice

For relationships to thrive such that the minority patients are happy with the diabetes care services they receive, the data revealed that the DSMLW would need to be part of the staff force. This would promote good working relationship amongst the practice staff themselves, which if absent has been seen to affect the coordination and delivery of diabetes services to EMGs.

At PR meeting 4, further enhanced at one-to-one interviews, participants discussed what can go wrong and what can go right in partnership working. Most participants felt that for the DSMLW service to be productive, the postholder will need to forge collaborative working relationship by developing and maintaining positive working relationship with patients and practice staff as well as partner agencies (Job description on Table 6.9). These relationships will be based on clear, mutually

agreed objectives and expectations for high quality patient care to which the DSMLW and staff commit themselves. The DSMLW would need to possess good interpersonal skills and be professional at all times as well as approachable. One staff participant described:

“Well, the link worker as a member of staff would be supported and work with everyone and in accordance with their contract to help these patients, interpersonal communication skills should be good, I think they can develop all these skills in the job, like most people do...but things can go wrong too that they don't fit into the job, you know” [MLW 2, One-to-one interview].

6.5.3.5.2. Working relationship with partner agencies

The data suggested that the process of building a collaborative relationship with external agencies and of making partnership-working a reality, is often beset by problems. This arises from lack of sufficient information and poor communication coupled with failure to thoroughly think through the agreements. Participants felt that as their practice cannot employ DSMLWs speaking all their ethnic minority languages, partnership-working would be essential with similar nearby practices. Forming partnership with three other general practices who share their vision of employing MLWs may be beneficial in meeting patients' needs.

Participants discussed ways in which partner general practices could each employ MLWs competent in different ethnic languages and put systems and processes in place that would ensure these MLWs can work across the cluster general practices in an accountable manner and in line with partnership agreements. An example was demonstrated in a group case study involving three practices: *‘Assume that your practice can only employ one Link Worker who speaks only 3 of the South Asian languages (Punjabi, Hindi and Gujarati), two nearby practices (A and B) can also employ a Link Worker each, Practice A Link Worker can speak Bengali, Urdhu, and*

Farsi and Practice B can speak Polish, French and Arabic. (a) How you effectively use your Link Worker to ensure he/she is meeting the needs of your ethnic minority patients with diabetes who speak these 3 languages (Punjabi, Hindi and Gujarati)? (b) How would you ensure that the diabetes needs of your patients who speak only Bengali or Urdhu or Farsi or Polish or French or Arabic are met? (c) How can the 3 practices work effectively together to ensure the THREE Link Workers are effectively meeting the needs of all patients with diabetes who spoke these NINE ethnic languages within the three practices?'

Based on this scenario, and after working in two groups, participants agreed that it would be crucial to have a written agreement amongst the cluster general practices to ensure the cultural needs of these patients were met. For example one group leader suggested:

"I think we need to basically have a meeting with all three link workers saying that you're going to provide a service for the patients with diabetes who speak Bengali, Urdu and Farsi at your surgery and we've got our link worker who provides a diabetes service speaking Punjabi, Hindi and Gujarati, so if you have patients who, when you need a link worker who speaks Punjabi or Hindi or Gujarati, then we can provide our link worker and can your practice do the same thing? We need to have one day or week or something like that and maybe have a link worker of other speaking languages to come and see the patients here. We can do this with the third practice as well. And I think if ...they're employed in our practice, I think it should be a written one – a written agreement, unless it's a voluntary link worker and then I think verbal is fine, but if someone is employed and we are paying the link worker, then the time should be agreed that you can go to another practice during these hours of the day and they can do it, so it has to be a written agreement within the other two practices" [HCP 1, PR meeting 3].

This suggestion was supported by all the other four participants present at this meeting. In order for the three general practices to work effectively together, another group leader took the floor:

"They would have to decide what day, what practice is going to do what language won't they I think? So everybody knows where they're going to be and what time of

the day and when, just so that there's no confusion if somebody turns up at the wrong surgery for the wrong patient, which happens occasionally with interpreters, perhaps, have fixed days for different link workers on elective appointments, where patients who speak the language of the link worker can be booked for their appointments... The advantages would be that the patient would turn up knowing that they'd have a consultation with a GP and somebody that could understand them, to get the full benefit of the appointment...Yes, so they'll get the full benefit from the time they've spent with the GP to discuss their problem" [Admin staff 2, PR meeting 3].

"And DNA [did not attend] rates will be less",

added the first group leader and concurred by all other participants.

6.5.3.6. Service commissioning and challenges

Regarding this theme, all participants were in agreement with the guidelines set in the National Service Framework for Diabetes (2001) and that *'everyone with diabetes deserves the highest standards of personalised diabetes care no matter where, when or by whom it is delivered* (Commissioning Diabetes Without Walls, 2009:5').

6.5.3.6.1. Sustainability and financial implications (managing present and future diabetes service provision)

Throughout the PR, participants reported that managing diabetes in the general population and in ethnic minority patients in particular was complex and very challenging. All except one participant [Admin staff 1] preferred that the future commissioning of diabetes care services should be based on 'needs' and not per 'head' as currently practised. During the PR meetings, this participant had favoured the commissioning based 'on needs' but changed their view to 'per head' during the one-to-one interview process as illustrated below. Participants who favoured the 'management based on needs' argued that in deprived and non-affluent area practices such as theirs, patients with diabetes do not only present with the diabetes

but with multi issues, some of which may be socially related. Therefore, for such patients to be managed holistically, it would require more time and resources than with patients in affluent locality practices who may experience fewer cultural issues.

For instance, one participant who like many favoured 'per needs' put the case:

"Per need absolutely, because if you're doing per head then you don't know what exactly you're doing, but if you're talking about needs, we're talking about the person, in a holistic way" [MLW 1, One-to-one interview].

A similar view was further expressed:

"...the needs of the patients are more important, so if you feel that that patient needs extra, or they need extra education, or they need to be monitored then that needs should be taken into account" [MLW 2, One-to-one interview].

However, the only participant who changed their view during the interview process commented:

"That's a little bit of a tricky one because I think possibly what you would find is that if they were paid on per need, the need of a patient, then there would be a lot of unscrupulous practice going on out there of surgeries then only wanting patients with long-term conditions, getting paid for a patient with a long-term condition, but not necessarily doing the work, so I think that would be a bit of a tricky road actually to go down. I think as it is being paid per patient head and not on what condition they've got works fine at the moment" [Admin staff 1, One-to-one interview].

The above view seemed to have been based on ethical issues because when probed and provided local examples of practices in deprived and affluent by this researcher, the participant responded:

"If appropriate systems and processes were in place to check unethical practice, then, yes..." [Admin staff 1, One-to-one interview].

Throughout the PR group meetings and participant observations, all participants showed an overwhelming enthusiasm by expressing the potential benefits the DSMLW service would have in their practice in particular and Coventry in general. However, at the one-to-one interview, one participant who felt very passionate about

the DSMLW model expressed a level of uncertainty regarding commissioning of the service and its long-term sustainability due to NHS financial constraints:

“I think the main issue will be around funding this service. The surgery itself, the funding that we get, I mean this year alone we’ve had quite a huge amount of money taken off us, both in our prescribing and in our PMS contract, so we’re already running at a loss and I think that’s the way it’s going to go. You know, the sort of NHS and the government are tightening the strings so much around primary care that in surgery there is no money... so you know” [Admin staff 1, one-to-one interview].

Regarding what should happen with data from this study and their input in designing this DSMLW framework, all participants strongly felt that it should be brought to the attention of diabetes service leads and clinical commissioning group leaders and put into practice. One patient participant expressed their commitment in supporting this study so that it could be used to improve practice:

“Each time I have to take a day off work to bring my mum to the surgery but if this service is available, I can just arrange for a taxi to bring her here and take her back after the doctor has seen her or even in the hospital, yes” [Patient 1, PR meeting 5].

Another participant who was agreeable with Patient 1’s view strengthened the case for action:

“I think it would be a shame after all these meetings now and what’s come out of them from this surgery alone, that there is a need, you know, even the patient representatives have agreed that there is a need, so I think it would be a shame if it fell on deaf ears that nobody looked into it a little bit more, or looked into where they could possibly do a trial to determine whether it was cost effective or not. But I think something needs to be done now for these patients, the CCGs need...especially as you [researcher] said ethnic minority patients who don’t speak English are not referred to DESMOND here [Coventry], it’s a shame because there are lots in our practice and they have more problems and need to know how to manage their diabetes. So setting up a service like this will benefit many patients with chronic conditions as a whole” [Admin staff 1, PR meeting 1].

6.5.3.6.2. Engaging and sharing good practice

The data suggest that although participants, especially staff, were aware and value the importance of sharing good practice with one another and bench-marking their practice with other practices, they were sometimes concerned if that would mean

less business. For example, at one stage during one of the PR meetings, practice staff participants expressed the view that they might need to have DSMLWs who worked exclusively in their general practice. However, they did not know how they could commission the service and/or employ DSMLWs who could speak all the languages spoken by their patients. Therefore, participants felt it would be useful to work with other practices so that the service could be more meaningful as commented by one of them:

“...there is funding that we could put a business plan out there on our own, but obviously you’d have to go with a lot of information to put it forward. They’d want to know figures and costing and expenditure and so forth and to outweigh it all, what is the actual benefit...so we can’t. But I think we can all work together for the good of all these patients, and if the CCGs puts one forward, it can benefit all the practices. Obviously, not all parts in the city will need this service” Admin staff 1, PR meeting 5].

This view was also emphasised by another participant:

“So we need to provide a good service so they keep coming back to us, but on the whole, we want to keep them [ethnic minority patients] healthy so they self-manage” [MLW 2, One-to-one interview].

Regarding how the different DSMLWs across cluster practices could share good practice, it was felt that regular monthly meetings amongst themselves or with the multidisciplinary teams involving the DSMLWs, practice nurses and each practice lead GP for diabetes may be a useful avenue to share common issues and support these link workers in their role. There may also be the need to include the hospital and community sectors in signposting the DSMLW service during community events as presented by one of the participants:

“...If we have this service [DSMLW], we need to be out there working together and making sure people know about this service, looking to see what community events are taking place. The hospital, the GP surgeries need to be represented there so that people get to know that it’s all about care, so if you care, I think you sort of...if you show care then people think they’ll put their trust in you and your service. They’ll think ‘they care about us, they care about our health. That’s why they’re out here. That’s why they’re attending our event.’ A lot of the time it’s all tick box exercises and people just don’t buy that anymore” [MLW 2, One-to-one interview].

6.6. Discussion

6.6.1. Discussion of key findings

The main focus of this study was to use evidence from previous chapters (Chapters Two, Three and Five) and explore cultural barriers impeding effective diabetes care provision to EMGs within a general practice. This was achieved in which the general practice prioritised and designed a Diabetes Specialist Multilingual Link Worker service framework as a means to cater for the needs of EMGs with diabetes. Whilst the study indicated some helpful practices, such as patients being consulted by healthcare professionals speaking the same language as the patients, unhelpful practices were also noted. Furthermore, there appeared to be problems associated with family members' involvement in patients' care. The data demonstrated that some family members who accompanied their relatives to their appointments, sometimes intentionally mistranslated/misinterpreted the information given by the healthcare professionals if they perceived that this information was not in the best interests of their family member. This is an unusual, but important finding, as wider literature has often showed family involvement as part of a solution (Narayan and Rea, 1997; DH, 2001; NICE, 2003; DH, 2005; DH, 2006). Further qualitative studies may be required to explore the impact of perceived 'useful' deception by ethnic minority patients' families in their care as a result of language barriers.

The findings demonstrated that cultural and linguistic differences between patients and staff added additional challenges in the studied general practice. This led to staff participants proposing and prioritising the design of the DSMLW interventional model. The methodological steps and joint collaboration of PR staff and patient

participants were fundamental to design the DSMLW framework. Throughout the DSMLW pathway, the data revealed that the assessment of cultural and linguistic issues should commence on patient's registration at the reception and be included in their care planning, and continued throughout the patient's lifetime with the practice. This proposed DSMLW service framework has potential to improve diabetes care within the general practice through cultural and linguistic concordances and to ensure that communication between patients and health care professionals are therapeutic and culturally adaptive.

It is hoped that if implemented, the DSMLW service will improve access of diabetes care services to their ethnic minority patients with cultural and linguistic barriers, which is in line with NSF for Diabetes (DH, 2001) guidance for healthcare professionals to tailor diabetes services to all individuals with diabetes irrespective of race, or gender or cultural background.

The fundamental difference from this proposed DSMLW model and the UKADS link worker model is that, whilst the latter focused on interpretation and liaison (O'Hare et al. 2004; Bellary *et al.*, 2008), which did not lead to improved changes in glycaemic control fundamental to diabetes care, the former has extended its role to requiring the link worker to have structured specialist knowledge in diabetes and to deliver structured and unstructured diabetes education programmes to ethnic minority patients. This is further discussed in Chapter Seven.

6.6.2. Strengths and limitations

The PR used different qualitative approaches (participant observations, PR group meetings and interviews) to investigate one specific area, which helped to uncover what was planned and what actually happened, which has strengthened this study. The proposed service framework now constitutes theory based evidence, which the general practice may have ownership of and can test in clinical practice. However, it needs to be acknowledged that without the determination coupled with background preparation of the researcher and support from the supervisory team, the aim of this study might have been far less successful. The study involved designing of a localised service model for ethnic minority patients with diabetes (not currently available in the city), therefore had a high interest factor. In fact, observing 321 clinical consultations/procedures and taking active part in some of these activities throughout the study duration is a strength. This enabled the researcher to experience the lived experience of the practice.

The contract stated that the full payment of £500.00 for the general practice and a £50.00 voucher to each patient would depend upon satisfactory attendance at the meetings. This might have influenced the good attendance rates, coupled with lunch/refreshments provided at each PR group meeting as well as texting participants on the morning of each meeting. In addition, the limited frequency of meetings (monthly) might have enhanced participants' attendance coupled with the fact that most of these meetings were conducted during lunch-time, and as such not onerously encroaching on individual workloads within the practice.

Limitations to this study include: the recruiting of only two general practices instead of the planned three, with one of the two recruited practices later on withdrawing from the study. It was anticipated that being a localised area of study with limited research, more practices would be interested to take part and the attendant results would be more generalisable. Another limitation is the conducting of both post-participatory one-to-one interviews with participants and the participant observations and PR group meetings by the same researcher. In so doing, participants might not have objectively shared their views regarding the PR group meetings and/or the participant observations at the interview process. An independent researcher (not involved in the previous two parts of the study) might have uncovered additional information. However, this was a PhD research study with limited funds. Specific figures of minority patients requiring specific ethnic languages within the general practice are missing from our data, which would have prioritised the types of DSMLWs most needed to direct service planners and clinical commissioning group leaders. Nonetheless, the fact that more than 50 percent of patients within this practice were ethnic minorities would mean attention should be drawn to policy makers as well as clinical commissioning groups. A detailed literature review was not undertaken following proposal by the participants to design a multilingual service. However, the researcher was aware of two existing MLW models which did not improve glycaemic control but had overall little benefits in ethnic minority patients (O'Hare *et al.*, 2004; Bellary *et al.*, 2008). As a participant and researcher in the PR, the researcher may have guided the rest of participants to reflect on why these previous models did not lead to much service improvement.

The once weekly full day participant observation (always on Monday) within the practice by the researcher may have been insufficient to fully understand the operational activity of that practice and to collect the data. However, this was in order not to encroach on the clinical activities of the practice, such as asking questions or seeking to participate during clinical consultations, thereby increasing consultation time-lengths. More working days and/or alternative days in the week might have facilitated better understanding and enabled the researcher to obtain any missing data such as specific primary languages spoken by all patients. Nonetheless, acknowledging this limitation lays foundations for improved future partnership-working and collaboration with the practice. Another limitation is the fact that whilst the PR group meeting participants proposed a need for both paid and volunteering MLWs, the designing of our model focused on the paid MLW to ensure commitment and accountability. However, it would be interesting if further studies could investigate the impact in patients' diabetes-related outcomes between these two types of MLWs.

6.7. Conclusions/recommendations

PR approaches have been successfully used worldwide, especially in developing countries, in healthcare research to engage participants as researchers themselves, which also worked well in this research (Braye and Preston-Shoot, 1995; Chambers, 1986; Swain and French, 2004). This approach has enabled the formation of a clear framework within which diabetes care services can be provided to ethnic minority patients with cultural differences. The resounding request received from all participants involved in the PR meetings was that this research be made public, especially to clinical commissioning group leaders and diabetes service leads with

the one hope that their plight might influence practice positively and contribute to future improvements in this under-researched and resourced area. To ensure this proposed DSMLW service framework would be tested, commissioned, be user-friendly and deliver better diabetes care services to the ethnic minority populations within the general practice and subsequently be transferable to other local and national settings, which could potentially lead to improvement in patients' diabetes health-related outcomes, our recommendations are therefore to:

- 1) Bring the findings of this study to the attention of diabetes clinical leads and clinical commissioning group leaders for possible actions,
- 2) Strengthen the leadership within the participated general practice, effective partnership working with partner agencies, meaningful engagement with ethnic minority patients within the practice, that would create a reflective learning culture and a more enabling strategic environment to all involved,
- 3) Ensure all practice staff develop cultural awareness, through training and personal development, which would be crucial in recognising and responding appropriately and constructively to the needs of ethnic minority patients,
- 4) Provide specialist (biomedical) and culturally-competent training to the DSMLWs, if implemented, (such as specific food compositions/diet relevant to the patients' culture), who can cascade some of the culturally-competent training to practice staff. All training should include elements of culture, language, religion and health literacy skills of the specific EMGs (Zeh *et al.*, 2012). This will also ensure meaningful interactions with these patients,
- 5) Have regular multidisciplinary team meetings involving DSMLWs, practice nurses, specialist diabetes nurses, dieticians, GPs, practice manager and

receptionists. These meetings will ensure that the pathway is appropriately implemented or revise to suit local needs,

- 6) Record the ethnicity and first language of all patients within the general practice. This aspect could be extended to all general practices with considerations for including this measure as one of the incentives for the commissioning specific DSMLWs,
- 7) Create an integrated IT system that will track all patients through the DSMLW service in order to inform the impact of the service and bench-mark practice with other general practices,
- 8) Design a pilot interventional randomised controlled trial to determine adaptability and long-term sustainability of the service by service providers and diabetes service commissioners. If successful, the service can be commissioned and subsequently be transferable to other similar general practices locally and nationally.

CHAPTER SEVEN

DISCUSSION OF RESEARCH FINDINGS: SYNTHESIS OF RESEARCH EVIDENCE

7.1. Introduction

Modern healthcare systems are facing ever increasing challenges to meet the diverse needs of EMGs, which require an understanding of the population-mix being served (Gill *et al.*, 2007; Bhopal, 2012). Recent evidence on diabetes care highlights the gaps in service provision and the variability of care across the UK (DUK, 2010; DH, 2012a; DH, 2012b; DH, 2012c; NHS Diabetes, 2013). The Best Practice for Commissioning Diabetes Services, an Integrated Care Framework recommends that *'putting the needs of the person with diabetes, and their families, first, is the cornerstone of integrated diabetes care'* (NHS Diabetes, 2013:36). The DEDICATED study set out to examine how health care professionals can work with EMGs in primary care to provide effective culturally-competent care services tailored to the needs of people with diabetes by identifying and exploring cultural barriers and seeking potential solutions. Thus, this PhD thesis presents contributions to the wider literature on diabetes in EMGs and possible health management solutions by recommending the implementation of effective culturally-competent diabetes care services such as the locally proposed 'Diabetes Specialist Multilingual Link Worker (DSMLW) service framework' [(Chapter Six)].

This chapter is divided into three parts: Part One presents the key findings of the research and discusses these key findings, important differences in the results, strengths, challenges and weaknesses in context with the wider literature and broader policy and health care agenda. The key themes of cultural barriers as

impediments to effective diabetes care services to EMGs, and the approaches to overcome or minimise these issues are explored. Part Two presents the main methodological strengths, challenges and weaknesses of the study, starting with a reflection on the practicalities of the research process, detailing planned activities and those that were executed. General lessons learned from completing this PhD thesis and how this researcher might have chosen to act differently if restarting this study, are presented. Part Three outlines the implications of the study for research and clinical practice, which may serve as guidance to policymakers, signposting some of the impacts of the study so far.

7.2. Part One

7.2.1. Statement of principal findings

The findings from this research showed both cultural barriers to the uptake of diabetes services across global multi-ethnic populations and also effective interventions to reduce these barriers. The first systematic review on cultural barriers in accessing effective diabetes care services identified eight cultural barriers from 22 included heterogeneous studies, perceived by EMGs as impediments to their care. These were participants' strong adherence to culture, religious beliefs, linguistic differences between them and their health workers, low health literacy levels, different beliefs about health and illness, belief in expert and professional support, low accessibility of culturally appropriate services/information and low concordance with Western professional advice. The second review elucidated approaches to overcome or minimise these barriers by investigating the impact of culturally-competent interventions from 11 experimental studies. Although these were heterogeneous studies, systematically assessing these interventions using CCAT, a

tool developed within this review study to determine cultural competence, showed that any structured intervention, tailored to EMGs by integrating elements of culture, language, religion, and health literacy skills, produced a positive impact on important patient outcomes.

In the cross-sectional general practice survey, one in three people with diabetes from the diabetic population was from EMGs. There was good reporting of ethnicity (94%) by general practices of their populations. Improved utilisation of diabetes annual checks was seen in the majority ethnic populations compared to EMGs. Fifty-six percent general practices delivered culturally-competent diabetes services scoring 90%-100%, 26% scored 70%-89% on the CCAT, and eighteen percent delivered a lower number of culturally-competent services (<70%). The main cultural barriers were language and strong traditions around food, coupled with less culturally competent providers, yet there was a lack of structured education programmes. Cultural issues were further explored and confirmed in one case study general practice, which selected and prioritised the designing of a Diabetes Specialist Multilingual Link Worker (DSMLW) model, aimed at bridging the inequality gaps in diabetes primary care service provision. Key elements of the model were training and education, function of the MLW, such as referral pathway, information sharing, partnership working, and service commissioning.

7.2.2. Discussion of principal findings arising from the research

This section discusses the key findings of the research in the context of primary research undertaken in Coventry and Warwickshire, secondary research, their strengths, weaknesses and challenges in relation to the wider literature by further

emphasising: continuing cultural barriers to effective diabetes care services; benefits of culturally-competent diabetes interventions; higher diabetes prevalence amongst EMGs in Coventry; good rates of general practices reporting of patients' ethnicity; lack of structured education programmes in Coventry; and the designing of the diabetes specialist multilingual link worker service framework. Although these results have been presented within their respective chapters (Two, Three, Five, and Six), they have been brought together in this chapter to strengthen the findings, and improve credibility, validity and generalisability of the primary research findings (Hussein, 2009).

7.2.2.1. Continuing cultural barriers to effective diabetes care services

Chapters One, Two, Five and Six demonstrated that diabetes does not impact upon everyone in society equally. Significant inequalities exist in the risk of developing diabetes, in gaining access to effective health services, and cultural barriers (such as language and religious differences) continue to prevent EMGs from receiving effective diabetes care services. Apart from three cultural barriers: different beliefs about health and illness, low concordance with Western professional advice, and belief in expert and professional support, identified in the secondary literature, the other predominant cultural themes identified were similar in both the primary and secondary literature. The research study has collated and demonstrated how these issues can affect members of EMGs from receiving effective diabetes. It is worth noting that the most commonly cited finding of cultural diversity in relation to language and strong traditions around food as barriers to culturally-competent service delivery, found in our primary data, is in line with the results of the systematic review (Chapter Two).

These factors may partly be attributed to less culturally-competent providers within healthcare settings leading to variation in service provision (Cone *et al.*, 2003; Mainous *et al.*, 2006; Zeh *et al.*, 2012). Implementing strategies aimed at reducing health inequalities was a core strand of *the NHS Plan*, as stipulated in the NSF for Diabetes (DH, 2001). However, in the wider contemporary literature, there appeared to be gaps in identifying and making reasonable adjustments to meet specific needs of EMGs, which would enhance their engagement and personal satisfaction with diabetes service provision and ultimately improve their health-related outcomes. For instance, from the literature accessed, only three studies (Lawton *et al.*, 2006; Sedgwick *et al.*, 2003; Brown *et al.*, 2006) specifically sought the views of EMGs on services or cultural needs, basing interventions on the authors' perceived interpretations of the cultural needs of minority populations. Furthermore, participating general practice staff in the participatory research reported that because their practice was located in one of the most deprived areas in the city, with high health inequalities around diabetes provision, ethnic minority patients had low knowledge levels about diabetes and its related complications.

In line with previous recommendations (Goody & Drago, 2009; Brown *et al.*, 2002; Hill, 2006; Stone *et al.*, 2013), more work is needed to improve cultural competences amongst health workers to empower patients to effectively self-manage their diabetes. Health policies should therefore be directed towards improving cultural competence training to facilitate partnership working between patients and their health care providers. This approach has proved to improve professional skills, cultural knowledge and attitudes amongst health care professionals enabling them to

work effectively in cross-cultural situations, thereby yielding positive health-related outcomes for their ethnic minority patients (Majumdar *et al.*, 2004; Khanna *et al.*, 2009). Furthermore, the Best Practice for Commissioning Diabetes Services, the Integrated Care Framework document has illustrated that *'providing better integrated diabetes care has been shown to improve patient experience, quality of clinical care and reduce hospital admissions for vulnerable patients (NHS Diabetes, 2013:36)*. The clinical commissioning group leaders and policy makers must strive with all diabetes stakeholders to remove the cultural divide between different providers and set realistic objectives for integrated care that will see more culturally-competent diabetes care services being commissioned, implemented and sustained, to meet the individual challenging needs of EMGs with diabetes. One of the ways to improve diabetes services for the EMGs could mean locally commissioning and piloting the DSMLW framework service described in Chapter Six, and if effective, could be sustained and be transferable to similar settings nationally.

Although most of this study's findings agreed with the wider body of literature, one of the key findings reported in Chapter Six suggests that there were problems associated with family members being used as translators/interpreters. In essence, the data demonstrated that some family members who accompanied their relatives to their appointments, sometimes intentionally mistranslated/misinterpreted the information given by the healthcare professionals if they perceived that this information was not in the best interests of their family member, termed as useful deceptions. This was a surprising, but important finding, as the wider literature has demonstrated that family involvement in patients' diabetes care is one of the beneficial solutions (Narayan and Rea, 1997; DH, 2001; NICE, 2003; Rhodes &

Nocon, 2003; DH, 2006; Gonzalez, 2008; NHS Diabetes, 2013). Although only two of these studies (Rhodes & Nocon, 2003; Gonzalez, 2008) did use family members as translators, the findings are consistent. This finding may have been uncovered as three different methods (participant observations, PR group meetings and semi-structured interviews) were employed. Further mixed qualitative exploration is warranted in this area to understand the role of family members in supporting relatives with low linguistic and health literacy competencies. The literature has illustrated that diabetes knowledge is a powerful perceived predictor of patients with diabetes (Baradaran & Knill Jones, 2004). Low English proficiency and low health literacy in a native language have been documented in the UK context as contributing factors to increasing social distance, reducing communication, which often threatens trust between patients and their health workers (Audit-Commission., 2000; Greenhalgh *et al.*, 2011). Appropriate linguistically-competent tools, including the Diabetes Literacy and Numeracy Education Toolkit that delivers multimodal presentation have been shown to have a positive impact on diabetes care services to EMGs (Roy & Lloyd, 2008, Wolf *et al.* 2009). Although challenging, in order to minimise the cultural barriers reported in this study and improve interactions/engagements between health workers and their ethnic minority patients, healthcare workers may benefit from cultural competence training, which has potential to improve their knowledge, confidence, and cultural awareness, to deliver culturally-competent care services (Papadopoulos *et al.*, 2004; Khanna *et al.*, 2009; Stone *et al.*, 2013).

7.2.2.2. Benefits of culturally-competent diabetes interventions

One of the key findings reported in Chapter Three was the paucity of culturally-competent health care service interventions in improving diabetes health related outcomes in EMGs, which was consistent with other systematic reviews (Saxena *et al.*, 2007; Whittemore, 2007; Alam *et al.*, 2008; Khunti *et al.*, 2008; Hawthorne *et al.*, 2010). The global evidence demonstrated benefits in using culturally-competent interventions amongst EMGs with diabetes. However, this study showed that the intervention must be structured incorporating elements of culture, language, religion and health literacy skills to produce positive impacts on a range of ethnic minority patient important outcomes, over and above standard clinical procedures. When the interventions used trained bilingual health advocates in story-sharing models over 12 weeks in an unstructured manner (Greenhalgh *et al.*, 2011), no differences in the patients' diabetes related outcomes were found at 12 months follow-up compared with baseline measures. Although the included studies/interventions were heterogeneous, it is important to emphasise that the culturally-competent qualities of each of ten positive interventions were systematically assessed and scored 70 percent or above on CCAT. The CCAT was developed by this researcher and successfully used to systematically assess the cultural competency of each intervention, and further validated in assessing the cultural competencies of diabetes services provided within the general practices in Coventry (Chapter Five). The wider literature searches and consultation with experts did not identify any previous tools for assessing cultural-competence of diabetes interventions. The CCAT is therefore novel as is the systematic assessment of the cultural competencies of each individual diabetes-related intervention.

Systematic reviews on diabetes-related interventions have not systematically assessed the cultural competencies of their interventions (Saxena *et al.*, 2007; Whittemore, 2007; Alam *et al.*, 2008; Khunti *et al.*, 2008; Hawthorne *et al.*, 2010; Wilson *et al.*, 2012; Pottie *et al.*, 2013). Following the last database searches in September 2011 for the two reviews (Chapters Two and Three), two further systematic reviews (Wilson *et al.*, 2012; Pottie *et al.*, 2013), which have investigated this area were retrieved, yet none of the previous and contemporary reviews included all three components (types of diabetes, all EMGs with diabetes as well as all study designs). The approach of widening the literature search to include all three components is novel and rigorous and should be replicated. The use of CCAT to systematically assess the cultural competency of the interventions for ethnic minorities with diabetes can be further structured to include the elements of culture, language, religion and health literacy skills. The programmes of education can be validated in all culturally-competent interventions aimed at EMGs with any chronic condition. Furthermore, the use of CCAT in assessing culturally-competent diabetes interventions may be emulated. Service providers should also adopt teaching and learning methods which meet cultural and community needs of the specific ethnic group (Hawthorne *et al.*, 2010).

Hawthorne (1990) noted that despite receiving the same education as the 'British' with diabetes, the South Asians did not understand their diabetes and the education was often not relevant to their diets or customs, which may have contributed to their poorer glycaemic control. An innovative healthcare intervention programme called Apnee Sehat (meaning 'Our Health' in Punjabi), a community interest company (CIC), was created in 2005 and commissioned by Coventry PCT in 2008. This

intervention aimed to address and tailor healthy lifestyle programmes to meet the individualised needs for health education and access for South Asian communities in response to a community request for lifestyle support.

This programme or intervention provided targeted education to hard-to-reach individuals in the South Asian community about risks and lifestyle choices and supporting behavioural changes to improve health outcomes, taking into consideration an awareness of their religions and cultural needs. For example, between June 2008 and May 2009, Apnee Sehat (2009) made contacts with 750 adult patients in Coventry; 101 went on to attend diabetes education, 643 attended healthy lifestyle and screening sessions, 20 attended shopping education and 40 participants attended cooking sessions. Of 605 participants who were screened for blood pressure, blood sugars and cholesterol, 459 (76%) had at least one abnormal result. In fact, of 211 participants who exhibited high blood glucose, 68 (32%) were already diagnosed with diabetes, 143 (68%) of these participants who were not previously diagnosed with diabetes, when formally checked were found to be diabetic. The majority of people who attended the education sessions reported experiencing diabetes education for the first time (Coe and Boardman, 2008). Those that had accessed other diabetes education had not experienced a tailored provision and no one reported having experienced diabetes education delivered in their first language. Post attendance follow-ups of diabetes education sessions, show almost all, (94%), of those attending reported having made positive lifestyle changes.

Despite this relentless work by Apnee Sehat CIC in successfully identifying possible undiagnosed people with diabetes in the community and encouraging contact with

their healthcare providers, NHS Coventry ceased the commissioning after one year. The reasons for decommissioning this service remain unclear to this researcher.

Further, built on the concept of Apnee Sehat, a local diabetes clinical team led by Dr Vinod Patel (Associate Professor in Clinical Skills at WMS and Honorary Consultant Physician in Endocrinology and Diabetes, George Eliot Hospital NHS Trust, Nuneaton), developed and tested specialised diabetes clinics called South Asian Specialist Intervention (SASI), where South Asian patients with diabetes were assessed and reviewed in a multidisciplinary setting at their own general practice and in their own language between January and May 2011. The patient-centred intervention allowed whole families to attend and provided a one stop shop by bringing nurses, physicians and dieticians all to the surgery. Of the 59 patients who took part in the study, each of them had a baseline weight, BMI, blood pressure, HbA1c and Cholesterol measured. The intervention consisted of a 30 minutes education session with a nurse, a 15 minutes consultation with a consultant diabetologist and a 15 minutes follow-up consultation four months later as well as telephone contacts in between by the nurse to monitor their progress. Participants were advised on behavioural and lifestyle changes which they had implemented as a result of Apnee Sehat's intervention.

The results presented by the researcher at the South Asian Health Foundation's 14th Annual conference in Birmingham on 21 November 2013, showed an improvement in HbA1c in 77% of total patients, with a mean HbA1c reduction of 1.3% after only 4 months. Blood Pressure improved in 79% of patients with a mean reduction of 15 mmHg systolic and 10 mmHg diastolic. Total cholesterol reduction recorded in 59%

of patients and overall cardiovascular risk reduction based on the Framingham model was significant with 56% of patients now having a cardiovascular disease (CVD) Risk score under 15%.

These results are interesting and are consistent with the findings from this thesis of the benefits of implementing linguistically-culturally concordant health workers in diabetes care service provision. Despite the decommissioning of Apnee Sehat CIC, it can be seen that it continues to be successful. It could be argued that the commissioning of such services needs to start with specific EMGs and then evolve to other minority communities over time, with diabetes commissioners constantly evaluating the service and improving incrementally. Knowles (1990) in outlining key issues for adult learners, cautioned that if an adult's experiences are ignored, the adult will perceive this as rejection of them as a person, not only of their experiences. As Wagner and Groves (2002:913) put it: *'evidence shows that we are not doing very well, and that the fault lies less in ourselves and more in our systems of care'*. Changes to the organisation and delivery of culturally-competent diabetes care services, will inevitably improve the quality of these patients' care and diabetes related outcomes, especially as the rates in EMGs continues to rise. Providing such culturally-competent services generally has the potential to improve health outcomes, increase the efficiency of clinical and support staff, and result in greater client satisfaction with services (Brach and Fraser, 2000; Anderson *et al.*, 2003). Therefore, the Apnee Sehat intervention can be re-evaluated drawing concepts from the story-sharing approach (Greenhalgh *et al.*, 2011; Hawthorne and Tomlinson, 1999), flash cards (Hawthorne and Tomlinson, 1997), clinical care planning (O'Hare *et al.*, 2004; Bellary *et al.*, 2008) and extended to other EMGs with diabetes. This

may appear challenging; however, it can potentially bridge some of the inequality gaps in accessing diabetes care services provision, reported in this thesis.

7.2.2.3. Diabetes prevalence amongst ethnic minority groups in Coventry (1:3)

The 2001 census shows that approximately 1 in 10 people living in Coventry was from an EMG. However, the population survey in which 52 percent of general practices participated (Chapter Five) found that one in three people living with diabetes in Coventry was from an EMG compared with one in five staff. This high proportion of ethnic minority people with diabetes was attributed to the challenging cultural barriers reported in Chapters Two, Three, Five and Six, coupled with lack of awareness of healthy lifestyle interventions, significant health inequalities and deprivation, as many ethnic minority people in the city live in socially deprived areas (Barker, 2006; Bellary & Barnett, 2007). This number is likely to increase due to the emerging EMGs from Eastern Europe, who may soon develop the disease as a result of cultural and linguistic issues not yet reflected in government healthcare policies. It is important to note that the Coventry Public Health Annual Report (2010) advocates healthy lifestyle initiatives and recommends a service model that describes the competencies and skill levels by practices to ensure effective utilisation of services, but falls short of recommending or adopting a model that allows for the needs of different ethnic minority populations locally.

A successful implementation of the proposed DSMLW framework service (Chapter Six) may be a starting point to aid ethnic minorities with or without diabetes to bridge some of the inequality gaps in accessing service provision. This researcher would also suggest that besides the reported cultural barriers discussed in this thesis, there

are other factors, such as genetic disposition, social and economic factors, which may contribute to the high proportion of EMGs having diabetes (Bellary *et al.*, 2008; IDF, 2009; DUK, 2010). From the wider literature especially in the UK context, studies have shown that EMGs are more susceptible to the disease and have poorer health-related outcomes than the white British population, with disease onset at younger ages (Chowdhury and Lasker, 2002; Oldroyd *et al.*, 2005; Roberts, 2007; Bellary *et al.*, 2008; Chiu *et al.*, 2011; Gholap *et al.*, 2011). By making commissioners aware of this research, they are more likely to pay close attention to the numerical recording of patient ethnicity found in this study (Chapter Five) and put in place more structured culturally-competent diabetes services in addition to promoting lifestyle interventions tailored to the needs of EMGs.

7.2.2.4. Good rates of general practices reporting of patients' ethnicity

Ninety-four percent of general practices (including all the four that participated in the pilot study) reported their patient ethnicities. This is an improved reporting rate compared to data collected in the pilot general practice survey (Zeh, 2010), where none of four participated practices reported recording ethnicities of their patients. This would imply that general practices took heed of the pilot study; hence the importance of sharing this aspect of good practice. Furthermore, the improved reporting rate may have been adopted by general practices due to the researcher reiterating the importance at primary care workers' multidisciplinary team meetings. In a recent similar survey involving thirty healthcare professionals (Iqbal *et al.* 2012a), 21 (70%) reported attempting to routinely collect some form of ethnicity data and those that did not collect these data cited lack of resources and 'self-reporting' as the main contributing factors coupled with sensitivity as the record requires asking

patients '*what they want it to be*'. The patients may not be willing to answer this question. Responding to this, patient participants in another survey conducted by the same authors, raised no objections to providing this information, provided the purpose for the data collection was fully explained to them (Iqbal *et al.*, 2012b). Many organisations strongly recommend the use of self-report as an ideal data collection method (Commission for Racial Equity, 2002; DH, 2005b). The Equality Act (2010) emphasises the importance of good-quality and complete ethnicity data to enable public services to use this information proactively to tackle health inequalities and target services appropriately. Despite these efforts to improve ethnicity data collection by healthcare professionals and the government, setbacks remain. Incomplete and un-validated data (making it difficult as to how best to collect the data or explain to patients how the data will be used), necessitate the development of appropriate training for healthcare professionals (Iqbal *et al.*, 2012a). The good reporting rates by general practices could indicate improved systems are now in place within Coventry practices to collect this information. However, regular auditing of ethnicity recording is warranted. This may guide diabetes service planners. In line with the principles set within the NHS Constitution (DH, 2010) and NSF for Diabetes (DH, 2001), the Best Practice for Commissioning Diabetes Service: an Integrated Care Framework recommends that '*services are designed to meet the patients*' needs rather than those of the service providers (NHS Diabetes, 2013:12).

Ethnicity in health research can provide valuable information about shared exposures for individuals with similar geographic origin, culture, language, beliefs about and access to health services (Mathur *et al.*, 2013). As discussed above, UK studies have shown higher rates of diabetes and cardiovascular disease, with poorer

health-related outcomes in EMGs than the white Caucasian populations, with the disease onset at younger ages, and at lower levels of risk (Raleigh, 1997; Chowdhury and Lasker, 2002; Kurian and Cardarelli, 2007; Bellary *et al.*, 2008; Gholap *et al.*, 2010). In essence, many authors have emphasised the fundamental role of patient ethnicity as well as language and race in healthcare service delivery (Commission for Racial Equity, 2002; DH, 2005a; Hasnain-Wynia and Baker, 2006; Melnick and Perrin, 2003). Many health care organisations have made calls to systematically document disparities and tailor healthcare interventions to improve the quality of care (National Research Council of National Academies, 2003; Hasnain-Wynia and Baker, 2006; Mathur *et al.*, 2013). However, this is often complicated by the fact that recording ethnicity or race or people's first language is not mandatory in many nations, neither is their inclusion in publicly funded research. For instance, unlike in the United States, there is no legal requirement for the inclusion of EMGs in publicly funded research which can provide the evidence base for guidance and policy tailored to ethnically diverse populations (Salway *et al.*, 2011).

Much of the evidence from UK literature demonstrates that hitherto, research on the UK population has not considered ethnicity as an explanatory variable of interest, often hindering investigations into ethnic healthcare inequalities (Oakley, 2006; Mathur *et al.*, 2013). The inclusion of patients' ethnicity will guide policy makers, service planners and clinical commissioning leaders to implement, evaluate and sustain individualised diabetes care services and enhance the quality of research. Valid and reliable data are fundamental building blocks for identifying differences in care and developing targeted interventions to improve the quality of care delivered to specific population groups (Hasnain-Wynia and Baker, 2006). Financial incentive

packages may be the way forward to motivate health care organisations to implement culturally sensitive training for both patients and staff. This potentially would help the organisations to understand their patients' needs, which will assist them in measuring disparities in care and initiate programmes to improve patient-centred care. The finding from this study should be regarded as a useful 'stepping stone,' that ethnicity data collection is feasible. However, the main challenge remains - whether diabetes service providers are prepared to fully commit resources using the ethnicity data to optimise the needs of EMGs.

7.2.2.5. Lack of structured education programmes in Coventry

NICE (2003) recommends 'structured education programmes' as key interventions, and specifies that these must be systematic, formally structured and be made available to everyone with diabetes at the time of initial diagnosis, and then as required, based on formal and regular assessment of need. NICE also clearly specifies that the education sessions should be accessible to all people with diabetes and should include cultural, ethnicity and geographical issues. However, our data (Chapters Five and Six) and liaison with local diabetes service leads did not identify any ongoing structured education programme for EMGs with diabetes in Coventry, which may reduce cultural and linguistic barriers. In addition, in Coventry, all local long-established UK NHS conventional structured patient-diabetes group education programmes, such as Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) [Skinner *et al.*, 2006; Davies *et al.*, 2008], Dose Adjustment For Normal Eating (DAFNE) [Heller *et al.*, 2002; Rogers *et al.*, 2009], or the Diabetes Manual (Sturt *et al.*, 2008), are delivered in English.

It is important to note that studies from over a decade ago have indicated that EMGs, of South Asian origin, in particular, have poorer knowledge of diabetes than their white British peers (Hawthorne, 1990; Simmons *et al.*, 1991). This knowledge is fundamental to good understanding of diabetes and glycaemic control to reducing diabetes complications (McCulloch *et al.*, 1983; Kronsbein *et al.*, 1988) and yet, there is little being done to improve structured education programmes for these people locally. As stated in Chapter One, nationally, there are few examples of successful structured culturally-competent education programmes to engage ethnic minority populations to improve their diabetes-related outcomes. The best known to this researcher include: the Leicester diabetes team led by Professors Melanie Davies and Kamesh Khunti of Leicester University who have been delivering DESMOND - Black and Minority Ethnic (BME) [an education course available in English as well as in Gujarati, Punjabi, Urdu and Bengali] in Leicester City since April 2009 (Mistry, 2010). In addition, the Leicester team and their partners have been working on *'DESMOND Foundation Study - A randomised controlled trial of the DESMOND Foundation Programme for people with established type 2 diabetes in a multi-ethnic population in Leicester and South Birmingham'* (Davies *et al.*, 2011) [see details of trial in Chapter One, page 18].

In addition, the Birmingham Community Healthcare is tailoring DESMOND diabetes education programme to people of South Asian origins with limited English-speaking skills by translating key instructions into Urdu, Bengali, Gujarati and Punjabi (<http://www.bhamcommunity.nhs.uk/news-archive/diabetes-bme-desmond/>). Another structured culturally specific self-management education programme for EMGs is the X-PERT Tower Hamlets programme, developed to specifically target local Muslims

in providing diabetes information using a DVD and website both at home and healthcare setting in appropriate languages.

Apart from the X-PERT programme, whose resources have been piloted and found to be extremely effective at providing advice and raising awareness of diabetes in the Muslim community (Diabetes Update, 2010), it is not clear if the impact of the other education programmes involving EMGs has been evaluated in order to be transferable to similar communities nationally. In another study (Gill *et al.*, 2010) adapting the X-PERT-based structured education programme to address cultural needs with respect to language, health literacy skills and accessibility, involving 96 South Asians with type 2 diabetes in London Borough of Hounslow, the intervention was delivered by a diabetes lay educator in either Punjabi or Hindi. This intervention found improvements in the primary outcomes (HbA1C, blood pressure, BMI and blood cholesterol and waist circumference) at 2 and 6 months follow-up when compared with baseline measures. The authors reported the intervention was cost-effective and well accepted by South Asian communities. Further, the authors reported that the positive effects in the primary outcome measures were due to changes in health, knowledge and empowerment of the patients to self-manage.

Studies have acknowledged the inclusion of cultural sensitivity in education interventions aimed at EMGs to be more meaningful (Stone *et al.*, 2005; Stone *et al.*, 2006; Hawthorne *et al.*, 2008; Khunti *et al.*, 2008; Gill *et al.*, 2010; Stone *et al.*, 2013). As diabetes knowledge and skills need to be conveyed to EMGs in a medium that they can understand, it is imperative for all local diabetes stakeholders (HCPs, diabetes leads, CCG leaders, community leaders and patients) to work in

partnership with one another in order to implement and deliver a joined-up integrated service, based on the needs of the individual person with diabetes (DUK, 2004, NHS Diabetes, 2013). This is further stipulated in Standard 3 of the National Service Framework (NSF) for Diabetes (DH, 2001:21), which states that:

“All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process.”

Successful implementation of education in an appropriate format and language will no doubt be challenging, unless specific ethnicity is applied, as some EMGs have higher learning needs (Rankin and Bhopal, 2001) and others (especially Bangladeshis) heavily rely on spoken dialects with no form of written format (Alam *et al.*, 2008). However, ‘Co-Creating Health project work’, an initiative based on the Chronic Care Model (Wagner *et al.*, 1996) which aimed to improve outcomes for people with long-term conditions through self-management support, conducted by this researcher in 2010, found that none of the staff delivering the locally-available structured education programmes was from an ethnic minority group or had received culturally-competent training in diabetes. Therefore, they could not fully meet the needs of EMGs with diabetes in particular, the areas of dietary advice, language, and cultural needs, which led to non-concordance and high ‘did not attend’ rates. This researcher strongly believes that more can be done to improve the culturally-competent training of healthcare professionals in the UK, especially for staff delivering structured diabetes education programmes. Undoubtedly, the commissioning of culturally-competent structured education programmes would initially prove costly for the NHS. However, if the service delivery is based on an integrated approach, it could reduce duplication and improve quality and productivity,

and lower costs resulting in improved streamlined experiences for EMGs with diabetes (NHS Diabetes, 2009). This has the potential to ensure that our local diabetes service delivery is designed and tailored around all individual patients with diabetes, rather than around the needs of the system.

7.2.2.6. Diabetes Specialist Multilingual Link Worker service framework

This section discusses the place of the Diabetes Specialist Multilingual Link Worker (DSMLW) service framework in the provision of culturally-competent diabetes care services in primary care by reviewing existing UK literature on the topic.

The concept of a multilingual link worker, defined broadly as a lay person trained to perform a defined role in promoting health for a specific community, has been cited in the UK literature for over twenty years with the Asian Mother Baby Campaign (Bahl, 1988), often acknowledged as pioneering the role. The challenge for healthcare researchers is the diversity of labels attached to the link worker's role: serving as interpreter, advocate, health educator, liaison, writing protocols, carrying out audits, and service provider (Eng and Young, 1992; Watson *et al.*, 1993; Hawthorne and Tomlinson, 1997; Khanchandani and Gillam, 1999; O'Hare *et al.*, 2004; Bellary *et al.*, 2008; Moss *et al.*; 2008). In Chapter Six, this researcher presented a DSMLW service framework, with specific illustrations on supporting the link workers to become specialists in their roles in order to support and empower EMGs with diabetes to self-manage their condition. In this section, we review the wider literature to understand the impact of this role in diabetes service provision, taking into consideration the areas in patient important outcomes that this role has improved or failed to improve, and make recommendations that could enhance the

implementation of the proposed framework, to deliver more benefits, not only to the patients with diabetes, but also to their families, studied general practice, and be transferable to wider clinical settings.

As demonstrated in Chapter Six, the studied general practice was mindful of the following:

1. Complexity of cultural and linguistic differences experienced within their practice;
2. Non-availability of any structured education programme for EMGs with diabetes in Coventry;
3. EMGs generally appreciate information delivered to them in a face-to-face manner and/or in support groups;
4. Need to improve diabetes services for their ethnic minority patients.

Therefore, the practice prioritised and designed a DSMLW service framework, with the vision that the framework could be commissioned and implemented to meet some of the needs of their ethnic minority patients with cultural issues on a face-to-face or group basis. This proposed DSMLW framework service (Chapter Six) has addressed some of these challenges being presented in diabetes service provision within the practice. These challenges are similar to those reported by other general practices in Coventry (Chapter Five). To comprehend the designing of the proposed DSMLW framework concept, it was important to revisit the existing literature involving multilingual link workers, to establish commonalities and divergences.

Hence, a detailed literature search from inception to May 2013 using Clinical Evidence Based Information Service (CEBIS) found seven previous UK-based studies that have focused on the use of multilingual link workers involving EMGs with diabetes (Wilson *et al.*, 1993; Hawthorne and Tomlinson, 1997; Khanchandani and Gillam, 1999; O'Hare *et al.*, 2004; Lloyd *et al.*, 2006; Bellary *et al.*, 2008; Moss *et al.*, 2008). These papers were analysed; all the link workers were proficient in specific, mostly South Asian ethnic languages (Urdu, Mirpuri, Pahari and Punjabi), including English and delivered diabetes services in patient's preferred languages. Whilst all link workers received unspecified training in their roles, one study reported structured training for the link worker, which also included diabetes knowledge (Moss *et al.*, 2008). Three studies reported that their link workers delivered structured diabetes education programmes to the EMGs (Wilson *et al.*, 1993; Hawthorne and Tomlinson, 1997; Moss *et al.*, 2008). All these three studies reported patients' satisfaction with the training (Wilson *et al.*, 1993; Hawthorne and Tomlinson, 1997; Moss *et al.*, 2008) as well as improved patient outcomes, especially in diabetes knowledge and HbA1C levels. For example, individual food value scores changed from 71% to 84% ($P < 0.001$), and HbA1C also slightly improved by $[-0.34\% (95\% \text{ CI } -0.81 \text{ to } +0.13)]$ (Hawthorne and Tomlinson, 1997).

Of the four studies (Khanchandani and Gillam, 1999; O'Hare *et al.*, 2004; Lloyd *et al.*, 2006; Bellary *et al.*, 2008) whose link workers delivered unstructured activities to the patients, two reported small improvements in patient important outcomes but no changes in HbA1C (O'Hare *et al.*, 2004; Bellary *et al.*, 2008). In one study (Lloyd *et al.*, 2006), the role of the link workers who assisted patients to complete the questionnaire had no direct impact on diabetes service delivery whilst another study

reported a high impact of the link worker's role in service delivery within the general practice (Khanchandani & Gillam, 1999). All link workers in these four studies were predominantly delivering **unstructured** interpretation and/or liaison services. None of the seven studies reported the delivery of group education by the link workers.

Comparing the findings from existing diabetes link worker models and the proposed DSMLW framework (Chapter Six), participants in the proposed model identified pre-requisites and specific competencies of the DSMLW as well as ongoing support and further training for the link workers, which will enable them to operate independently and refer on patients to healthcare professionals as required. Whilst the roles of the wider link worker models were primarily limited to interpretation and liaison (O'Hare *et al.*, 2004; Bellary *et al.*, 2008; Lloyds *et al.*, 2006), the DSMLW model also includes having specialist knowledge and delivering face-to-face unstructured and structured one-to-one and/or group education sessions to ethnic minority patients with diabetes as well as cascading some of the culturally-competent training to healthcare professionals within their practices. In effect, a face-to-face approach provides the patient the opportunity to develop a rapport with the health worker directly giving the information, ask questions and clarify issues. In the same regard, within support groups/group education, the information is delivered in the context of a trusting relationship, with people facing similar challenges. In the two UK Prospective Diabetes Study RCTs (O'Hare *et al.*, 2004; Bellary *et al.*, 2008), the link worker model did not improve HbA1C levels. In these two examples, whilst all patients received face-to-face educational input and the access to link workers was expected to increase compliance, these components were not structured and may have failed to deliver the desired results leading to minimal benefits and lack of cost-

effectiveness. In fact, the remit of the link workers was to work alongside the practice nurses and the diabetes specialist nurses to enhance patient understanding and compliance rather than directly delivering the service. This was anticipated as in all complex interventions, many of these factors interact with each other making it difficult to ascertain the benefits of these components individually (Campbell *et al.*, 2007).

The DSMLW model has recommended both in-house and external basic courses as well as specialist skills and training (Chapter Six), including continuous supervision of the DSMLW as well as monitoring and assessing of their training needs. The model also specifies the pathway and what should happen in the case of non-availability of a DSMLW. Another essential requirement for the proposed DSMLW is the minimum education qualification of *'NVQ Level 3 or diploma level or its equivalent, as well as an appropriate ethnic language qualification of at least GCSE level'*, which was not found in existing link workers' job descriptions. Furthermore, the DSMLW will have three months induction period of twenty interactive full-day sessions, which will include visits to some partner agencies. This proposed approach thus includes aspects of training that have not been explicitly explained in previous multilingual link worker models. In addition, unlike the previous models, cited above, which used one teaching/learning aid and/or not explicitly described methods, the proposed framework will use written, audiovisual and video aids in patient education depending on the patient groups because patient learning needs differ. As such, each of the aids will have important roles to play individually. For example, the use of pictorial flash cards with Pakistani British patients impacted positively on diabetes knowledge and HbA1C (Hawthorne and Tomlinson, 1997). In effect, in the proposed

model, the DSMLW will possess and/or undertake diabetes and cultural competence-related training, belong to the same ethnic minority community, and therefore, the DSMLW will be linguistically-culturally-diabetes-competent. This may ensure that ethnic minority patients are adequately supported and empowered to self-manage their diabetes, in line with NSF for Diabetes (DH, 2001) guidance requiring adequate tailoring of diabetes services to ensure holistic and meaningful interactions with the patients. In line with the systematic review findings (Chapter Three), a recent review by Pottie et al. (2013) revealed that ethnic minority patients with language barriers and limited access to diabetes programmes benefitted from interventions by using health workers from the same ethnic group. These interventions promoted culturally acceptable and financially affordable food choices using local ingredients, resulting in improved HbA1C levels, at least in the short term.

Therefore, the proposed DSMLW model is a significant outcome of this PhD study. Whilst the literature suggests benefits in using multilingual link workers with appropriate ethnic language skills and cultural concordance, the proposed model differs from existing frameworks in the UK context as it has taken into consideration the pitfalls and strengths of the previous models. It is recommended that diabetes clinical leads and clinical commissioning groups test this framework further in practice. As noted by Khanchandani and Gillam (1999:993), *'it is easier to train a link worker to carry out nursing duties than to teach a nurse to speak an Asian language fluently'*. This would apply to any ethnic languages not spoken by any healthcare professionals involved in diabetes primary care service provision. Therefore, well designed and implemented healthcare courses and support for link workers in

diabetes patient education could lead to improvements in diabetes self-management, patients' experience and diabetes-related outcomes in ethnic minority patients.

7.3. Part Two

7.3.1. Practicalities of the research process

This section briefly reflects on the practicalities of the research process, strengths and limitations of the research methodology and design, detailing planned activities and those that were executed, general lessons learned from completing this PhD thesis and how this researcher might have chosen to act differently if restarting this study.

7.3.2. Planned research vs. completed research

This study was originally designed to address the following primary research question: *'How can/do NHS healthcare systems provide culturally-competent services in order to provide healthcare and promote health in EMGs with diabetes?'* In particular, the target patient groups were people of African-Caribbean and South Asian origins, using two systematic reviews, population general practice survey, interviews with 24-30 ethnic minority patients, 16-24 healthcare professionals/local trainers preferably from different cultural backgrounds, and 6 healthcare commissioners). However, like most research projects, a number of challenges were encountered along the way but successfully managed. The three primary challenges of research were the outcome of the upgrade process, recruitment difficulties and the systematic review process.

Firstly, during this researcher's upgrade from Master of Philosophy to Doctor of Philosophy (MPhil to PhD) level in February 2011, the panel was concerned that the

key milestones identified in the proposal (primary data collection) might not contribute to generalisable new knowledge due to the earlier evidence from the two systematic reviews (Chapters Two and Three). The panel suggested that the aims and research questions be reviewed and the research methods reviewed appropriately, and submitted in a six-page follow-up report within eight weeks, to ensure that the PhD project was fully grounded. The feedback was acted upon to their satisfaction, which led to modification of the primary research question to: *'How could NHS health care professionals work with EMGs in primary care to provide effective culturally-competent care and services tailored to the needs of EMGs with diabetes?'*

Therefore, one of the study objectives: *'Investigate the cultural needs of EMGs with diabetes and the effects on their day-to-day and family lives'* was changed to *'Develop and implement a culturally-competent service that is tailored to the individual needs of EMGs with diabetes within case study practices.'*

By revising this objective, the planned population general practice survey remained unchanged. However, the interview data collection with patients and staff was replaced by planned implementation research. The latter was done to promote the uptake of clinical research findings from the two systematic reviews (Chapters Two and Three) including other evidence-based practices into clinical practice, to improve the effectiveness, reliability, safety, appropriateness, equity, and efficiency of diabetes services provided (Eccles *et al.*, 2009). Within the implementation research, planned data collection methods included participant observations, implementation research meetings, and post-implementation research interviews with patients and staff within selected general practices. However, this research did not finally include

implementation research methodology. This is because the findings from Chapter Three on *'culturally-competent intervention for improving diabetes healthcare interventions'* did not warrant the justification of implementation research. Ten out of eleven culturally-competent interventions involving EMGs with diabetes found that *'any structured intervention, tailored to EMGs by integrating elements of culture, language, religion, and health literacy skills, produced a positive impact on a range of patient important outcomes'* (Zeh *et al.*, 2012:1237).

The only intervention (Greenhalgh *et al.*, 2011), which did not produce improved outcome measures generally was unstructured. The authors reported that unstructured story-sharing models were used to deliver the group interventions, which could mean that some groups did not cover key learning components essential for holistic self-management (Osborne *et al.*, 2007). Furthermore, in some interventions, the outcome measures did not improve significantly. Consequently, the above finding became less reliable to proceed with implementation research. It was replaced with participatory research (Chapter Six), still using participant observations, participatory research meetings and post-participatory research interviews with patients and staff participants for data collection. Therefore, it can be seen that the original focus of the research was amended following the upgrade process and during the research, that is, replacing the proposed interviews with 24-30 ethnic minority patients, 16-24 staff and 6 healthcare commissioners with the PR research. The planned interviews with healthcare commissioners were not included in terms of data analyses as it was deemed too complex for a PhD project. Although adapting these changes strengthened the research, needless to say, any such shift

in any developing research project made the completion deadlines more difficult, despite tight time-management

Secondly, as with the implementation research, the PR approach intended to purposively recruit three general practices based on the findings from the population general practice survey (Chapter Five) and the geographical location of practices with high EMGs with diabetes showing (a) high performing culturally-competent activities (n=1), (b) less performing culturally-competent activities (n=1), and (c) low number of EMGs with diabetes and less culturally-competent services (n=1), to inform practices demonstrating lower performance and/or still meeting minority patients' needs. However, as reported in Chapter Six, recruitment proved challenging and it took over four months to recruit two general practices, both with a high number of EMGs with diabetes and low culturally-competent services. However, one of the general practices withdrew consent after six weeks, including the use of the data already collected.

In addition to the recruitment difficulties, when the research protocol was submitted for Research and Development (R&D) for approval, the need for additional recruitment sites was not envisaged. However, when the DSMLW service framework was being designed, it became pertinent to further explore this area with the experts who have lived or are living through the role. There was evidence of similar roles being undertaken in Coventry and Warwickshire Partnership Trust and North Warwickshire. NHS R&D approvals were obtained and two multilingual link workers interviewed. Although there was a lengthy waiting time for the approval (8 weeks),

which was above the stipulated NHS R&D 30 days approval target, however, by including these interviews, the quality of the PR study was enhanced (Chapter Six).

Thirdly, there was no formal written protocol, such as those used by Cochrane Database of Systematic Reviews (detailing the role of each within the review team), for the two systematic reviews (Chapters Two and Three). This extended the time spent in completing the review process (see under lessons learned below).

7.3.3. Lessons learned and what this researcher would do differently

DEDICATED research was a competitive research training fellowship, which had gone through vigorous assessment by experts nominated by the funders. Therefore, this researcher did not anticipate the upgrade panel would amend the research question. The lesson learned from this incident is always to have an open mind during an assessment such as this. The feedback undoubtedly improved the quality of this research, thus leading to designing the DSMLW service framework, which currently does not exist in the city. If the researcher were to start the study again, a careful reflection of the initial findings from the two systematic reviews would be undertaken, to ensure the thesis would lead to new knowledge. Following the feedback from the upgrade panel, immediate contingency plans were not in place; it took four weeks to reach agreements with supervisors on the alternative pursuit because of the reorganisation of the NHS, in particular in primary care with the proposal of clinical commissioning groups, to be led by GPs, dissolution of Primary Care Trusts, and Strategic Health Authorities. All these proposed changes made it difficult to engage with primary care leaders, as most were concerned about the future of local health services as well as their roles.

Regarding the second challenge relating to the methodological change, this researcher learned about the importance of undertaking feasibility studies prior to any research study and the various pressures facing general practices, such as the proposed changes within the GP contracts and GPs required to improve capacity with less money. Such pressures make general practices less interested in engaging with research, perceived by some as 'time-consuming' and 'not cost effective,' which was commonly reported by staff during the general practice survey (Chapter Five) and also by the practice that withdrew consent in the PR (Chapter Six). There were only twenty eligible general practices meeting the inclusion criteria, and the 'Participant Information Booklet' stated that the researcher will work with the practice staff one to two days per week as well as hold monthly meetings with practice staff and patients. This, in hindsight, heightened the anticipated complexity of the process, such as potential disruption to their daily service delivery, and should have prompted the researcher to plan ahead. Therefore, in future, the researcher will be more proactive by liaising with the key organisational gatekeepers, to understand potential barriers to recruitment and design contingency plans to overcoming them. In the current scenario, contingency plans were only initiated after two months without recruitment, after initial invitation letters had been sent out. However, the researcher's initiative of liaising with his supervisors prior to making the third and final phone contacts (as per ethics approval) direct to the practice managers made the positive difference. In reflection, this showed effective project management and networking skills exhibited by the researcher in resolving things that were doable and escalating them when there was a need.

Like the two cases discussed above, not having a formal written protocol for the systematic reviews, was daunting. To overcome this challenge, the researcher effectively managed the process by planning monthly meetings with the review teams (his supervisors) and weekly individual meetings with each of the co-reviewers to compare agreement levels of the screened articles. This was the first time for this researcher to carry out this type of research. The search strategy and the inclusion criteria were peer reviewed by supervisors as well as specialist librarians. However, each stage of the review process was complicated, such as independently screening and selecting the eligible papers, having a bibliographical software reference manager, data extraction, contacting authors for additional information, quality assessment of the included papers and synthesising the results. Therefore, the researcher learned the process when the data collection had already commenced.

Overall, the two systematic reviews (Chapters Two and Three) taught the researcher much about in-depth pre-planning, evidence synthesis, assessing training needs, the importance of scoping an area of interest to uncover if there is need for further investigation, the value of a pre-written protocol, and the difficulties created for future researchers if interventions/studies are not described in detail and results not reported clearly. The researcher consulted the 'Understanding Research and Critical Appraisal' a taught Masters' degree course which offers different research methodologies/methods, including systematic reviews. Some systematic review techniques were acquired from this course as well as literature from the Cochrane handbook, which improved the final outcomes of the two completed reviews. These two systematic reviews have been peer reviewed and published, and the reviewers

raised no concerns relating to their methods. In fact, the review (Chapter Three) has been appraised and approved by the University of York Centre for Reviews and Dissemination and included on Database of Abstracts of Reviews of Effects (DARE) in October 2013 (Centre for Reviews and Dissemination, 2013).

7.3.4. Reflection

Despite the challenges presented above, the whole endeavour in completing this research thesis was a personal, educational and professional experience. Indeed, the co-operation and support received from all the research stakeholders (participants, supervisors, funders, collaborators, family and friends) were very instrumental in the success of these research efforts. The various training undertaken during the PhD duration also empowered the researcher to complete this study. The delays of nine months in completing the PhD project within the three years of the then Warwick University standards, which have now been increased to four years since October 2012, partly due to personal circumstances, coupled with ill health (see below) have resulted in the researcher's ability to 'let go' of the uncontrollable in life and focus, through achievable goal-setting, on effecting changes that would subsequently lead to desired outcomes.

Overall, as a result of this research, this researcher has acquired new knowledge and skills, and came to know of over ten experts; and will continue to maintain and develop further contacts for collaborative research activities.

7.3.5. Key strengths and weaknesses of the methodology and design of the study

The scoping of the evidence allowed the researcher to identify previous work in this area and successfully design this study using secondary and primary data collection

methods, which has given a better understanding of the studied phenomenon. The survey described in Chapter Five was underpinned by previous piloting involving four Coventry inner-city practices (Zeh, 2010).

This pilot survey recommended that general practices record the ethnicity of all their patients, and report these data centrally to assist in the planning and commissioning of effective diabetes services. This work, in addition to the researcher's special interest in diabetes and ethnicity, became a motivating factor for the researcher to further explore this area in a logical order using systematic reviews, quantitative and qualitative methods to complement the richness of the data as well as maximise the findings (Hemingway and Brereton, 2009; Harden, 2010). The results were widely disseminated, which impacted the 34 participated general practices to improve the ethnicity recording of their patients to 94 percent within three years. The designing of CCAT and successfully using it to systematically assess culturally-competences of previous (Chapter Three) and current (Chapter Five) healthcare interventions is another strength as well as a fundamental finding.

The main weaknesses to this study are methodological issues; first, the inability to conduct meta-analyses in the two systematic reviews (Chapters Two and Three) due to the heterogeneities of the included studies. However, including mixed study designs in each of the systematic reviews was also a strength. Previous systematic reviews have focused on specific methods and populations in order to perform meta-analysis (Hawthorne *et al.*, 2010). Another major weakness in study is the inclusion of the multilingual link worker literature review in the Discussion Chapter rather than in the PR Chapter itself (Chapter Six). However, this was so because the designing

of the proposed framework in Chapter Six emerged during the PR process. Being a PhD research project with limited resources and strict timetable, it was not practicable for the researcher to complete a detailed literature review while the PR process was already in progress. The multilingual link worker literature review, presented above, was undertaken to make sense of the existing frameworks and to guide recommendations arising from this research thesis. However, this did not compromise the overall aim of this study as the researcher was aware of other link work models (O'Hare *et al.*, 2004; Bellary *et al.*, 2008).

7.3.6. Contextual and other methodological strengths and limitations

7.3.6.1. Contextual limitations and strengths

This research thesis was part of a competitive NHS West Midlands training fellowship aimed to develop research leadership and research capability amongst nurses, midwives and allied health professionals (NMAHPs) in the West Midlands. As a regional award, it was not an NIHR portfolio study and had limited funding to cover the researcher's salary, plus a yearly £2,500 towards research costs. Being a challenging area where EMGs are significantly under-represented in research, this researcher applied for the adoption of the study by the local Primary Care Research Network and Diabetes Research Networks, in order to meet service support costs. However, the applications were unsuccessful as the award was not nationally competitive. Therefore, service support costs were met by the researcher and an unrestricted educational grant from Novo Nordisk and TAKEDA pharmaceutical companies.

The research topic was chosen due to limited research in the NHS into understanding the impact of cultural barriers impeding EMGs from accessing effective diabetes care services, and culturally-competent interventions to improve health outcome measures in EMGs with diabetes. The research has been undertaken at a time of significant changes within the NHS. It commenced when the Labour government was in power, where there was no mention of the dissolution of the primary care trusts (PCTs) or the strategic health authorities (SHAs). The emergence of the Coalition government in May 2010, dominated by the Conservatives, disbanded the SHAs and PCTs on 31 March 2013 as part of the Health and Social Care Act 2012 (DH, 2012d), in favour of clinical commissioning groups, led by GPs, coupled with major financial cuts. Whilst PCTs were largely administrative NHS bodies, responsible for commissioning primary, community and secondary health services from providers, the SHAs supported and managed the performance of PCTs in the exercise of their functions. In fact, the UK Parliament Health and Social Care Act 2012 is regarded as the most extensive reorganisation of the structure of the NHS in England (Delamothe and Godlee, 2011).

Although these are real challenging moments both for the diabetes service providers, and ultimately, the patients, there may be opportunities within these reorganisations to improve and tailor diabetes services to the needs of EMGs. The Best Practice for Commissioning Diabetes Services, an Integrated Care Framework has already outlined its vision which, if implemented, will see the needs of all patients with diabetes and their families coming first as the cornerstone of integrated diabetes care (NHS Diabetes, 2013). Therefore, the timing of this study is both a strength and a challenge. This study has potential to influence the diabetes leaders and

healthcare commissioners to implement more culturally-competent services. The challenge would be how to invest in culturally-competent diabetes care services.

7.3.6.2. Inclusion of all ethnic minority groups and all types of diabetes

Besides the pilot general practice survey, this study was founded upon two systematic reviews (Chapters Two and Three), which included all EMGs with all types of diabetes as well as any research design (from wide range of sources including experts) globally. This meant that this study was able to investigate the international perspective before focusing on the local perspective of the studied phenomenon. In effect, the findings from these reviews demonstrated cultural barriers to diabetes service uptake across international multi-ethnic populations and effective interventions, which led to the applicability of these factors to investigate these issues in one multicultural UK city with over 4.4 percent diabetes prevalence rate. These findings further led to the PR process (Chapter Six). Therefore, this design was robust because previous systematic reviews have limited their search to specific EMGs (Whittemore, 2007; Alam *et al.*, 2008; Gill *et al.*, 2007) or study types (Sexena *et al.*, 2007; Hawthorne *et al.*, 2010) or type 2 diabetes (Whittemore *et al.*, 2007; Alam *et al.*, 2008; Hawthorne *et al.*, 2010).

7.3.6.3. Use of mixed methodology as a pragmatic approach

As discussed in Chapter Four, mixed methodology represents a social science research approach, which encourages the integration of both quantitative and qualitative methodologies (Morgan, 2007; Symonds and Gorard, 2010), which is in line with pragmatism where the focus is on the problem in its social and historical context rather than on the method (Evans *et al.*, 2011).

The use of this mixed methodology in primary data collection showed that quantitative and qualitative research belong to different paradigms, underpinned by different philosophical positions, addressing different research themes and questions, differing in their data collection and data analysis methods (Bergman, 2011). The methodology worked well in this research [using mixed methods of quantitative and qualitative methods (Chapter Five), and qualitative (Chapter Six)] as well as in previous research studies (Greenhalgh *et al.*, 2006; Lloyd *et al.*, 2008b), by complementing each other to reach a better understanding of the primary research question. This is a strength, which is viewed by many authors as a way forward for researchers to bridge the rift between qualitative and quantitative research in clinical practice and increase the rigour of the research results (Onwuegbuzie and Leech, 2005; Creswell and Plano Clark, 2007).

Furthermore, the usefulness and reliability of this methodology can be gauged from the results that arose from this thesis, which echoed the findings of previous studies in this area. However, this methodology has also been seen as a weakness by purist constructivists (such as Glaser and Strauss, 1967) or positivists (such as Cohen, 1980). In addition, according to Denscombe (2008), some researchers tend to use MM pragmatically as a means to avoid biases inherent to single-method approaches. However, the pragmatic use of MM in this thesis has strengthened both the integration of quantitative and qualitative methodologies both in a single study (Chapter Five).

7.3.6.4. The researcher

The researcher is of African ethnic origin, and not competent in South Asian or Polish languages, which were the ethnic languages spoken by most of the EMGs within the participating practice. However, this did not impact on the overall research process; instead, it did engage participants who were more open on sharing their views regarding diabetes services provision during the face-to-face meetings. This may be attributed to the effective communication skills of the researcher as well as being approachable and a good listener. Furthermore, the dual role as a nurse and researcher within the general practice appeared to have impacted positively as the researcher took part during consultations by giving patients healthy lifestyle advice on diabetes self-management as well as delivering some of the interventions such as checking the blood glucose levels, taking blood pressures, including some administrative activities, in accordance with the ethics approval.

In order to strengthen the methodological design and execute this research thesis, this researcher undertook cultural competency training. In acquiring this knowledge, four key areas were crucial: cultural awareness, cultural knowledge, cultural sensitivity, and cultural competence (Papadopoulos *et al.*, 2004; Papadopoulos, 2006). According to Gerrish & Papadopoulos (1999), a culturally competent researcher needs to develop both 'culture-specific' and 'culture-generic' competences. Culture-specific competence refers to the knowledge and skills that relate to a particular ethnic group, which enables the researcher to understand the values and cultural prescriptions operating within a particular culture. Culture-generic competence refers to the acquisition of knowledge and skills that are applicable across ethnic groups.

Although cultural competence training is widely recommended for health workers, such as nurses and doctors, there was no evidence of this training or courses being delivered locally or received by healthcare professionals working with EMGs with diabetes. Therefore, as a PhD research fellow in health sciences undertaking research on diabetes on EMGs, it was important to develop this knowledge. In his quest for knowledge, the author came across the work of Irena Papadopoulos, Professor of Transcultural Health and Nursing at Middlesex University, London. The Papadopoulos, Tilki and Taylor Model for Development of Transcultural Competence (1998), which aims to help healthcare professionals to deliver culturally competent care that ultimately ensures high quality care for their patients, was inspirational. This model consists of four key elements as cited above, which are further outlined and illustrated below on how they instilled the required knowledge and skills for this researcher to design the research questions, general practice questionnaire, topic guide interview questions, and to successfully execute this research project.

7.3.6.4.1. Cultural awareness: This is the first stage in the model, which begins with an examination of one's personal value base and beliefs. This raising of self-awareness contributes towards one's understanding of the nature and construction of their cultural identity. At the same time, a person becomes more aware of their own cultural background, which is a major factor in shaping one's values and beliefs which in turn influence one's health beliefs and practices, and in effect constitutes an essential first stage in the process of achieving cultural competence. This researcher was knowledgeable in this stage prior to commencing the research, being an ethnic

minority himself, who has lived in Caucasian majority population countries for twenty years.

7.3.6.4.2. Cultural knowledge: This second stage knowledge can be gained from several disciplines, such as sociology, psychology, medicine, anthropology, health sciences as well as relationships or communications with people from different cultural groups enabling the researcher to see similarities as well as differences (Papadopolous, 2006). The methodological design work (Pilot General Practice Survey, Chapters Two, Three, Five and Six) illustrates a contribution in this area in relation to acquiring knowledge around EMGs generally and the cultural factors impeding access to effective diabetes care and deriving possible solutions on how to overcome them.

7.3.6.4.3. Cultural sensitivity: This third stage constitutes how professionals view people in their care, such as establishing trust, empathy, acceptance, respect for one another, communication skills in advocacy, negotiation, appropriateness and respect in inclusive research (Papadopolous, 2006). For example, considering research participants as true partners is a crucial element in anti-oppressive practice (Dalrymple & Burke 1995). This researcher has always demonstrated this in his professional roles, such as being culturally sensitive to the needs of patients based on religion, culture or sex. This knowledge was applied in designing and executing this study.

7.3.6.4.4. Cultural competence: This final stage demands the synthesis and application of previously gained awareness, knowledge and sensitivity (Papadopolous *et al.*,

1998; Papadopoulos *et al.*, 2004). This is needed for application of practical skills such as assessment of need, clinical diagnosis and other caring skills, recognising and challenging discrimination and oppressive practices. As demonstrated throughout the thesis, from data collection to dissemination, all previous points have been applied. For example, the knowledge acquired from the secondary data was applied in primary data collection, designing the research process, during fieldwork, and in writing up this thesis.

In addition, the regular correspondences between this researcher and experts in this area, such as Professors Rena [Irena] Papadopoulos, Raj Bhopal, Kamila Hawthorne, Mark Johnson, Trisha Greenhalgh and Julia Lawton, with at least one face-to-face meeting with all these experts except the last two, further enhanced the researcher's cultural competency level. Therefore, in designing and undertaking this research, the acquisition of cultural competency has been a personal and professional gain, which is a strength. It will always be a valuable asset throughout the researcher's professional and research life.

The methodological limitations to this research include:

7.3.6.5. Interview transcripts

The transcripts of the interviews conducted with the eight participants (Chapter Six) were not returned to them for validation. The sixth step of Colaizzi's (1978) procedural framework used by some qualitative researchers requires the researcher to return the description to its original source for confirmation of validity. However, as explained in Chapter Six, the first interviewee objected as they had built a trustworthy rapport with the researcher during the seven months PR within their

practice. The researcher in subsequent interviews did not follow up this offer, which, after reflection, was deemed necessary.

7.3.6.6. Designing the general practice survey

The Culturally-Competent assessment Tool (Chapter Three) comprised of ten questions was not used to design the 35 questions in the population survey (Chapter Five). This made the assessment of cultural competences within each general practice difficult. However, this appeared to be a strength as well as a weakness, because by not using it to design the questionnaire, the questionnaire served as its validation.

7.3.6.7. Participatory research recruitment difficulties

This was a localised research study involving ethnic minority patients with diabetes, with a high interest factor, where little research has been done. It would have been thought that many general practices, would engage even without payment in order to improve their patient care. However, some practices did not participate because the proposed £500 for the PR was not cost effective. Due to limited resources earmarked for the project, the researcher could not contact the Ethics Committee to increase the payment. Furthermore, this researcher suffered poor health and bereavement during the study that required three months temporary withdrawal from the course. This increased the amount of time that was spent on the project.

7.4. Part Three

This section outlines the implications of this study for research and practice as well as its outputs so far.

7.4.1. Further implications of the research

Although this research suggests that some improvements are being made in diabetes service provision to EMGs, there are still some challenges on how to tailor cost-effective diabetes services to their needs, therefore, warranting further research to:

1. explore health workers' perceptions and understandings of ethnic minority people's eating patterns (and why), and how these might guide the advice given to these patients. This might clarify the perceptions about South Asian foods, and establish if health workers themselves hold incorrect or stereotypical perceptions;
2. investigate if formal culturally-competent training for diabetes service providers generally produces a positive effect in diabetes-related outcomes in ethnic minority populations. Healthcare organisations should have culturally-competent staff and services, which should result in positive health outcomes to EMGs;
3. culturally-competent interventions should include cost-effectiveness evaluation in their design as well as the satisfaction levels of patients and service providers;
4. explore the role of family members in supporting relatives with diabetes who have low linguistic and health literacy competencies;
5. target recruitment issues and training of multilingual health care professionals to improve the diabetes knowledge and health literacy of EMGs;
6. develop psychological and behavioural interventions to effect changes from diabetes-related external to internal locus of control.

7. a pilot interventional randomised controlled trial is required to determine adaptability and long-term sustainability of the DSMLW service to inform service providers and diabetes service commissioners.

7.4.2. Implications for practice

The syntheses from this research showed cultural barriers that impeded EMGs from accessing effective diabetes care and effective diabetes interventions. If acted upon, the findings may guide the planning and commissioning of culturally appropriate diabetes services tailored to the needs of ethnic minority populations. The implications for practice include:

1. Specific and complex health care needs assessment of EMGs requiring specialised interventions tailored to their needs;
2. Universal healthcare delivery may not be appropriate for EMGs globally, requiring partnership working between the service providers/service planners and the EMGs to instigate and sustain meaningful change;
3. Acknowledgement of both dominant and minority cultures and their influences on concordance and seeking to influence those aspects perceived to be changeable by the patient through patient-centred education. This would mean all health workers need to develop cultural awareness, which would be crucial in recognising and responding appropriately and constructively to the needs of ethnic minority patients;
4. Designing of community-led interpersonal health information sources/centres using existing networks, which include written and audio-visual materials associated with specific ethnic minority populations' cultural beliefs. However, future research is warranted to investigate the effectiveness of such initiatives

in promoting service utilisation and behaviour change in diabetes self-management;

5. Specialist (biomedical) and culturally-competent training to healthcare professionals as well as the DSMLWs (such as specific food compositions/diet relevant to the patients' culture), is essential. All training should include elements of culture, language, religion and health literacy skills of the specific EMGs (Zeh *et al.*, 2012). This will also ensure meaningful interactions with these patients;
6. Healthcare organisations should provide culturally competent staff and services;
7. Collection of ethnicity data via self-reporting and first language of all patients within general practices. This may improve the planning and commissioning of diabetes primary care service provision;
8. Assessment of the cultural competency level of every healthcare intervention designed for EMGs. The CCAT resulted from this study may further be validated for this purpose, as it proved successful in two studies (Zeh *et al.*, 2012; Chapter Five). This would have implications in practice as their cost-effectiveness could then be evaluated to inform future commissioning of these services and buy-in by their respective service commissioners;
9. Reduction of duplication of diabetes services and ensuring effective auditing. An integrated IT system should be created that can track all patients through the systems such as via the DSMLW service will inform the impact of the service that can be bench-marked with other similar general practices. Useful IT systems are already underway, for example, the Eclipse IT system (which allows the transfer of patient data between some general practices and

secondary care in Coventry); and the Diabetes Manager, (which enables remote review of primary care case notes by secondary care, currently used by University Hospitals Coventry & Warwickshire NHS Trust / Coventry and Rugby CCG). The effectiveness of these IT systems needs to be evaluated.

7.4.3. Research outputs

This PhD research has been widely disseminated so far:

1. One peer-reviewed publication has resulted from this research (Zeh *et al.*, 2012) [Chapter Three]. This study has been cited in department of health publications and by academics. Furthermore, this article was rated by BioMedLib as the eighth out of twenty topic publications in this domain on 10 December 2013. Chapter Two work (a systematic review on 'cultural barriers impeding EMGs from accessing effective diabetes care services), is in press and the publication is planned by Diversity and Equality in Health and Care journal in March 2014. Chapter Five data has been drafted and to be submitted to the Diabetes Care Journal. There are also plans to write up the work presented in Chapter Six for appropriate journals.
2. The launching of the research engaged all stakeholders by including ethnic minority patients with diabetes, healthcare professionals in primary and secondary care, healthcare commissioners as well as academics, who suggested useful ideas to take the project forward. A summary of the discussion was also mailed out to all delegates.
3. Five different updates including key findings on the study have featured in the 'Participate Magazine,' [Issue 13, 2009; issue 16, May 2010; volume 6, summer 2012; volume 8, winter 2012; volume 10, summer 2013]. This is a

quarterly primary care newsletter, implemented by West Midlands South Primary Care Research, geared toward updating healthcare professionals with the latest developments in local research.

4. Two press releases by UHCW NHS Trust Communications: '[Research sheds new light on providing effective diabetes services to Ethnic Minority Groups](#), 31 August 2011 and [Research sheds new light on providing effective diabetes services to Ethnic Minority Groups](#), 26 June 2012.
5. A summary of the general practice survey findings was sent to all participating practices. A summary of the PR findings has also been sent to all participants.
6. Various aspects/findings of the research have been presented at twenty-seven meetings/conferences; local (n=9), national (n=10), and international (n=8), see details in Appendix 23. A consolation prize was won at Primary Care Diabetes Society conference, Birmingham, 16-17 November 2012 for the poster presentation titled '*A single city case survey: How do we deliver diabetes care to ethnic minority populations?*'
7. The researcher has held formal meetings with three local clinical commissioning group leaders and three diabetes service leads to discuss the research key findings. Five out of six who granted audience to this researcher confirmed they would definitely support the commissioning and implementation of the DSMLW service framework in Coventry, and one said they would like to see a business plan to decide. A business plan for the service in addition to other diabetes services is being submitted.
8. This research led to the designing of the CCAT, which was novel, and can be further validated in any chronic disease involving EMGs.

9. The DSMLW job description was validated by all seven participants involved in the PR monthly group meetings, with all agreeing that it represented their views.
10. As discussed above, at the pilot stage of this study, there was no evidence of general practices collecting the ethnicity of their patients in broad categories. However, at the population general practice survey, 94 percent reported completing this activity. Therefore, this study has created awareness locally. It can be argued that appropriately recording patients' ethnicities will provide an optimistic baseline for planning and commissioning services, which might have important implications for practice and, particularly, the need to develop processes for use in other cities to audit their health care provision for similar populations.

7.5. Chapter summary

The principal aim of DEDICATED study was to develop an in-depth understanding of what cultural barriers exist within diabetes services and how these services can be tailored to meet the needs of EMGs with diabetes. This chapter has therefore brought together the research evidence by appraising the key findings of the research, which have addressed this research question, in addition to the sub research aim, discussing them in context with the wider literature. The key findings discussed were: continuing cultural barriers to effective diabetes care services; benefits of structured culturally-competent diabetes interventions; higher diabetes prevalence amongst EMGs in Coventry; good general practice reporting rate of patients' ethnicity; lack of structured education programmes in Coventry; and a proposed diabetes specialist multilingual link worker service framework which, if

implemented can bridge some of the inequality gaps found in the local diabetes primary care service provision. This was followed by a reflection on the practicalities of the research process, outlining the general lessons learned from completing this PhD thesis including the methodological strengths and limitations of the research as well as the implications of the research.

In relating the key findings with national policies, the evidence demonstrated that significant health inequalities were associated with specific communities in societies that develop diabetes more than other groups due to several factors, such as cultural beliefs or living in socially deprived areas. The implementation of National Service Framework for Diabetes (2001), which is in its final year plan, had stipulated guidance on the minimum standards of diabetes care that should be offered to all patients. The document has succeeded as well as failed in some areas both locally and nationally. Part of the failure locally could be attributed to diabetes service planners and commissioners. For example, no evidence of structured culturally-competent diabetes education programmes was found, which is mandatory and fundamental to all newly diagnosed people with diabetes.

The introduction of the Quality and Outcomes Framework (QOF) indicators (a primary care-based financial incentive infrastructure development for diabetes care) in 2004 was to improve the quality of care for all patients with diabetes (DH, 2004; DH, 2009). However, there is limited evidence to show improvements in diabetes-related outcomes in the general diabetes population as a whole and in EMGs in particular (QOF, 2011). Such incentives should support reductions in health inequalities, for example, by focusing on those members of the local population who

have the greatest need for specific interventions (DH, 2009), such as the EMGs with diabetes.

It will be hoped that the Best Practice for Commissioning Diabetes Services document implemented in March 2013, designed to bring about integrated diabetes care for all people with diabetes (NHS Diabetes, 2013) will ensure that equitable diabetes services are implemented to meet the increasing needs of EMGs with diabetes. Because the increase in diabetes rates in UK EMGs is likely to continue, with diabetes management typically involving a considerable element of self-care, it is imperative that health policies support the implementation of culturally appropriate interventions aimed at facilitating effective diabetes service access to EMGs. Undoubtedly, promoting and supporting diabetes self-management in EMGs would imply better understanding of cultural barriers by service providers and ensuring effective communication in appropriate languages between patients and their providers from diagnosis throughout the patient's lifelong diabetes journey (NICE, 2003; Wilkinson and Randhawa, 2012).

The next chapter concludes this PhD thesis and proposes the way forward.

CHAPTER EIGHT

CONCLUSIONS AND THE WAY FORWARD

8.1. Summary of the main findings

The primary aim of this research was to develop an in-depth understanding of what cultural barriers exist within diabetes services and how these services can be tailored to meet the needs of EMGs with diabetes.

The objectives of the study were as follows:

1. To identify cultural barriers that hinder ethnic minority people with diabetes from accessing effective diabetes care services;
2. To examine the impact of culturally-competent diabetes care interventions in improving diabetes-related outcomes in EMGs;
3. To investigate diabetes primary care service provision to EMGs and commissioning of such services in a typical ethnically mixed medium-sized UK city;
4. To design an effective culturally-competent diabetes care service that can be implemented in primary care for EMGs with diabetes;
5. To make recommendations on delivery and commissioning of diabetes care services to meet the needs of EMGs locally and nationally.

These issues were addressed using a two systematic reviews and mixed methods to provide a comprehensive insight into the phenomenon from a qualitative and quantitative point of view and to better understand the research question as these two methods are known to complement each other. Initially two systematic reviews were undertaken to accumulate and inform the literature in this area. Both confirmed

cultural barriers to the uptake of diabetes service across international multi-ethnic populations and effective interventions. The first review focused on cultural barriers preventing ethnic minority populations' access to effective diabetes care and showed that cultural and linguistic barriers did compromise the diabetes care services received by these groups, and affected their glycaemic control.

The second review studied ways to overcome and/or minimise these barriers by examining the impact of culturally-competent diabetes care interventions on diabetes-related outcomes in ethnic minority populations from eleven experimental and innovative studies. A CCAT designed to systematically assess the cultural competency of each intervention found that: *'any structured intervention, tailored to ethnic minority groups by integrating elements of culture, language, religion, and health literacy skills, produced a positive impact on a range of patient important outcomes'* (Zeh *et al.*, 2012:1237).

Based on evidence from the two reviews, and the pilot work involving four Coventry inner-city practices (Zeh, 2010), a population general practice semi-structured survey was conducted to map this evidence onto the Coventry city population and its health care provision. Again, using the CCAT to examine the cultural competence of the diabetes services within each of the 34 (52%) participating general practices, this single city survey demonstrated the challenges found in existing literature across international multi-ethnic populations. These findings combined with the evidence from the two reviews informed a participatory case study research project in one local general practice with a high number of EMGs with diabetes receiving lower culturally-competent services. Both culturally appropriate and non-culturally sensitive practices were observed, with some ethnic minority patients with cultural differences

being consulted by healthcare professionals from the same ethnic backgrounds as well as children used to interpret for their parents, and at times patients with language barriers consulted without the use of any form of interpretation.

Due to the many cultural barriers between the patients and service providers in the participating practice, the practice prioritised and designed a DSMLW service framework, with the hope that it could be commissioned and implemented to improve diabetes services to these patients in their practice. The diabetes service leads and CCG leaders have recently showed interest in the service framework which, if commissioned, will need to be piloted and, if successful, can subsequently be transferable to other similar general practices nationally.

8.2. Implications of the research and recommendations for implementation

The findings of the research clearly show that despite improvements in diabetes services to EMGs, there are still challenges on how to tailor cost-effective diabetes interventions to meet their needs. The research suggests that if acted upon, the findings may impact practice positively by guiding the planning and commissioning of culturally appropriate services tailored to the needs of EMGs.

Combining these findings in the context with the wider literature highlights:

1. The paucity of culturally-competent interventions to improve diabetes-related outcomes in EMGs with diabetes, and ways of improving primary diabetes care services to this group of patients. Redesigning culturally-competent delivery systems can enhance access to diabetes care and efficiency, but

they need to factor the shifts in roles and responsibilities that are impacted by such change. These changes require adequate cultural competence training of health workers and the integration of support systems to foster successful collaboration. These aims are in place although in practice much still has to be done.

2. EMGs with diabetes face cultural barriers in accessing effective diabetes care services and the implementation of effective culturally-competent diabetes care interventions tailored to their needs is likely to bridge the inequality gaps in diabetes primary care service provision, and improve the diabetes-related outcomes of these hard-to-reach groups. The work has proved that meaningful interactions between active minority patients and service providers are often beset by challenges, some of which have been discussed in relation to the wider literature.
3. Reducing health inequalities was a core strand of the NHS Plan (2000) and the NSF for Diabetes (DH, 2001) clearly stipulates how this should be implemented. In practice, developing and implementing culturally-competent diabetes care services for EMGs is slow. DEDICATED study has investigated this area and made recommendations on how CCG leaders and diabetes service leads may improve this area, particularly in Coventry, where one in three people with diabetes from the diabetic population is from the minority groups compared with one in ten from the general local population. These service developments should include the active involvement of the specific EMGs, to ensure that these services are appropriate to their individual needs, such as ethnicity, language, culture and religion. Further PR studies like the one in Chapter Six, including ethnic minority patients, together with their

service providers, CCG leaders and carers, should encourage effective partnership-working.

4. The objective of this research should be to maintain and improve diabetes services, applying clinical audit criteria and performance management measures where necessary, as well as measuring, monitoring and checking health inequalities. If successful, the recommendations can be transferable to other health care settings.

8.3. Conclusions

Overall the findings of this PhD thesis suggest that for those delivering diabetes care to EMGs services should aim to provide a patient-centred model which integrates primary and secondary care, and ensures effective deployment of resources, thereby minimising duplication through effective communication.

Fundamentally, both the CCAT and the DSMLW service framework that emerged from this PhD project are novel innovations. They can be adapted to improve diabetes care locally in Coventry and to other cities and regions.

Using the CCAT to assess existing interventions, the study proposes that future culturally-competent interventions should include elements of culture, language, religion and health literacy skills tailored to the individual ethnic minority populations. These components should be assessed to ensure they meet the needs of specific ethnic minority populations. In the absence of linguistically and/or culturally-competent staff, a Diabetes Specialist Multilingual Link Worker Service framework is recommended to support primary care. Whilst EMGs need to preserve their cultural

identities within their host nations, they should be encouraged and assisted by service providers towards community integration of their host nations. Future studies and clinical audits involving EMGs, who are currently under-represented in clinical research, are warranted.

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APPENDICES

Appendix 1: A pilot general practice survey

Delivering diabetes care to ethnic groups: A pilot general practice survey

Peter Zeh

Article points

1. Ethnic groups (EGs) have higher rates of type 2 diabetes and comorbidities than the general population.
2. Delivery of diabetes care to EGs is challenging because of cultural, communication and comprehension difficulties.
3. This pilot study of current diabetes service provision to EGs in four GP practices in Coventry highlighted areas of need.
4. Recommendations for improving diabetes care for EGs include cultural competence training for staff, better resources, and more effective diabetes networking among GP practices.

Key words

- Cultural sensitivity
- Ethnic groups
- Pilot study
- Type 2 diabetes

Author's details can be found at the end of the article.

Most ethnic groups (EGs) in the UK have an increased risk of type 2 diabetes and associated comorbidities. Many live in socially deprived areas and have high levels of illiteracy, which may impede access to diabetes care. However, little is known about the cultural issues and challenges facing primary care service providers and the additional resources needed to deliver diabetes care to EGs. This pilot study aimed to elicit an understanding of current GP practice regarding EGs, using a specifically developed survey questionnaire to highlight areas of need. Findings show that practices work autonomously but are conscious of the need to deliver high-quality diabetes care (by employing staff speaking some EG languages, for example) and identified a lack of resources and culturally sensitive awareness to meet EGs' needs. Recommendations for improving service provision to EGs include cultural competence training for staff, better resources to support a streamlined service within practices, and effective diabetes networking among GP practices.

Diabetes is a chronic, metabolic, and usually lifelong, condition, making it a major health issue. Characterised by increased morbidity and mortality resulting from related complications – especially cardiovascular, renal and neurological – it represents a lifelong learning process for people with diabetes and healthcare professionals alike. Diabetes also has major social and economic implications for the NHS (Department of Health [DH], 2003; Roberts, 2007) because of the considerable costs associated with the management of these complications.

The prevalence of diabetes is increasing rapidly, both locally and nationally, especially among ethnic groups (EGs), who are particularly susceptible to the condition (Barker, 2006; Barnett et al, 2006).

In Coventry, the recorded diabetes prevalence in 2006 was approximately 3.5% (around 12 000 people), with higher rates in EGs (up to three times higher in African-Caribbean people and six times higher in people of south Asian origin) compared with the majority white population (Barker, 2006). The number of people from EGs with diabetes is unknown.

Page points

1. Ethnic groups (EGs) have poorer disease management, low adherence to treatment and medications, poor outpatient attendance and poor glycaemic control.
2. Anecdotal evidence suggests that GP practices find it difficult to access the resources necessary to meet the diverse needs of their patients.
3. The aim of this pilot study was to identify how local practices deliver diabetes services to people from EGs with diabetes, in particular those of south Asian origin (Indian, Pakistani and Bangladeshi), and also to discover what additional resources are needed to improve the service provided.
4. Four GP practices in Coventry (three with high numbers of EGs and one with high performance based on the QOF) were surveyed by means of a questionnaire to identify how local practices deliver diabetes services to people from EGs with diabetes.

Coventry is a typical UK city, with relative affluence alongside pockets of severe deprivation. Most EGs live in socially deprived areas with higher levels of illiteracy and insufficient knowledge of the English language, diabetes and the healthcare system, which may impede access to diabetes care (Bellary and Barnett, 2007).

There is widespread recognition of the benefits of managing diabetes in primary care settings and also by referral to hospital-based diabetes clinics (Goyder et al, 1998; Khunti et al, 2000; Rhodes et al, 2003; O'Connell, 2006). However, preliminary evidence reveals two main areas of concern:

1. The quality of healthcare delivered to EGs by healthcare professionals is inadequate (Johnson et al, 2000), primarily because there is a strong cultural element associated with the provision of care to EGs and some NHS staff are not sufficiently culturally competent.
2. Compliance with instructions for diabetes management by people from EGs is poor (Johnson et al, 2000): they have poorer disease management, low adherence to treatment and medication, poor outpatient attendance and poor glycaemic control.

Moreover, anecdotal evidence suggests that GP practices find it difficult to access the resources necessary to meet the diverse needs of their patients. This article describes a survey of four GP practices in Coventry undertaken to gain an understanding of current service provision for EGs and to highlight areas of need.

Aim of the study

The aim of this pilot study was to identify how local practices deliver diabetes services to people from EGs with diabetes, in particular those of south Asian origin (Indian, Pakistani and Bangladeshi), and also to establish what additional resources are needed to improve the service provided. The findings could potentially influence practice both locally and nationally.

Evaluation design

Following consultations with an expert focus group, a quantitative method, using a semi-

structured questionnaire (25 questions), was employed for data collection.

Methods

A variety of techniques were used to design the semi-structured questionnaire; the investigator (PZ) assumed the role of a "critical friend" to improve and enhance the overall design. The 25 questions were devised by the investigator, following three structured, quarterly meetings held to ensure that the questions were both meaningful and practical to complete.

The quarterly meetings were hosted by Edgwick Medical Centre, Coventry, which has a very high number of south Asian people. Meetings were attended by one GP, a consultant in public health, a diabetes specialist nurse (DSN), a community project facilitator, a practice nurse, a practice manager, a patient representative from one of the target EGs, plus the investigator.

A purposive sample of four inner-city GP practices in Coventry (three with high numbers of people from EGs and one with high performance based on the QOF) was selected. Lunch meetings and presentations were organised at each practice (except the host practice) and were open to all staff members. There was at least one GP present during each meeting.

In each practice, a questionnaire designed to evaluate the services was given to the practice manager, who was considered likely to provide an objective overview of the care provided. The questionnaire sought information on diabetes cases, diabetes service delivery to EGs, the staff's diabetes skills and knowledge, additional resources needed, and commonly encountered cultural problems.

The questionnaire was piloted at the four practices between September 2008 and February 2009. Three of the four practices returned their questionnaires within 3 weeks and the other within 3 months.

The collected data were initially analysed by the investigator and subsequently analysed independently by two colleagues from the Warwickshire Institute for the Study of Diabetes, Endocrinology and Metabolism research team. A

meeting was held and results were compared to ensure agreement.

Results and analysis of the findings

The data collected highlight both positive and negative outcomes from six emerging themes:

- Diabetes prevalence within each practice.
- Staffing level.
- Language and communication.
- Knowledge and training.
- Cultural issues.
- Diabetes services and policy.

The findings are discussed in detail below.

Prevalence of diabetes

Within the four practices – designated A, B, C and D – there was a total of 1142 people with

diabetes (A = 208, B = 440, C = 168 and D = 326; *Figure 1*). Of these, 965 were from EGs (84.5%). This high proportion of EGs is due to the fact that three of the four practices are located in Foleshill, an area with a high concentration of south Asian people.

Of the 965 people with diabetes from EGs, 947 (98.1%) had type 2 diabetes (A = 189, B = 406, C = 30 and D = 322). This supports current epidemiological data showing that prevalence of type 2 diabetes is increasing at a faster rate in the UK (74%) than in the US (41%) (González et al, 2009). *Figure 1* shows the proportions of people from EGs with type 2 diabetes and other people with any form of diabetes in each of the four practices, expressed as numbers and percentages.

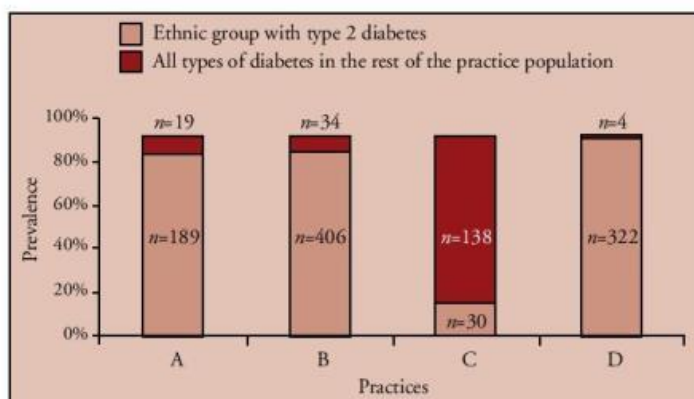


Figure 1. Comparison of the prevalence of type 2 diabetes in ethnic groups with the prevalence of all types of diabetes in the rest of the practice population in each of the four GP practices.

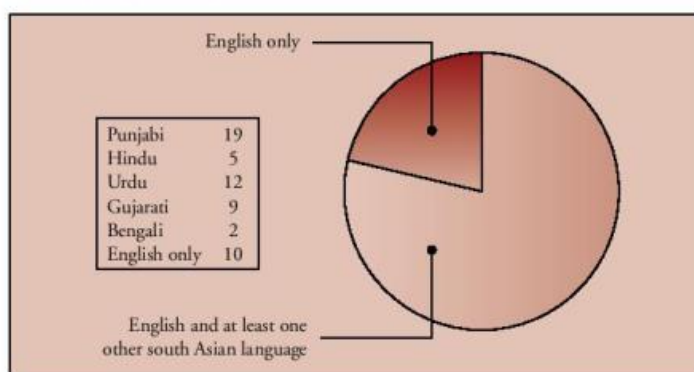


Figure 2. Distribution of staff speaking south Asian languages and those speaking English only, in the four GP practices.

Staffing

The four practices had 47 staff (A = 9, B = 13, C = 12 and D = 13), of whom 11 (23.4%) were full time. Of the 47, 37 (78.7%; A = 9, B = 13, C = 2 and D = 13) spoke one or more of the south Asian languages. Again, this can be attributed to the fact that the three practices in Foleshill would have felt the need to recruit more staff who could speak the languages understood by their patients (*Figure 2*).

Knowledge and training

The training and knowledge level of staff leading diabetes care reported by the four practices was generally very good. All four practice managers stated that their GPs receive up-to-date diabetes information from various sources: in-house training from GPs with special interest in diabetes (GPSIs) and hospital consultants, clinical meetings, reading relevant journals, and attending formal courses during study days. Also, all four practices had a lead nurse for diabetes who had undertaken formal training leading to a qualification in diabetes care and who continued to receive updates in diabetes.

However, three of the four practices did not know whether Coventry had a central register for diabetes. The reason for this may be that it is not currently mandatory for practices to report the number of diabetes cases to the

Delivering diabetes care to ethnic groups: A pilot general practice survey

Coventry PCT or Strategic Health Authority. A central register would be useful for providing data on the number of people with diabetes, which could be used to assist with planning the service.

Language and communication

Language is a means of communication, and effective communication in healthcare delivery, whether through language or non-verbal communication methods, is paramount. Communication can be a complex issue, especially where people speak different languages; it requires an understanding not only of language but also of culture.

Anecdotal evidence suggests that a high proportion of the south Asian population in Coventry, especially those living around Foleshill, do not understand English. Effective communication therefore requires the use of their native languages. Five south Asian languages (Punjabi, Hindi, Urdu, Gujarati and Bengali) were identified as commonly spoken in Coventry. The proportion of these languages spoken by the 47 staff was as follows: Punjabi (19), Hindi (5), Urdu (12), Gujarati (9) and Bengali (2) (*Table 1*).

One practice had staff who spoke all five languages between them. No staff from the other three practices spoke Bengali, so they had to rely on hired translators. Three of the four lead nurses for diabetes spoke at least one south Asian language (not Bengali or Urdu) and would therefore need translators for effective communication with people whose languages they did not speak. This is exactly what was achieved in three practices where they had designated translators/interpreters for the languages.

Cultural issues

Relatively few studies have explored possible cultural barriers and lack of cultural competencies by healthcare professionals, which may hinder the delivery of quality diabetes care in the UK (Crowley, 2000; NICE, 2003; Goenka et al, 2004). Healthcare professionals need to be aware of differences between the dominant culture and that of the target patient group, i.e. they should take account of the individual's background and deliver care and services in a way that is perceived to be non-discriminatory (Cone et al, 2003). Lack of cultural competencies by some staff has been cited in studies, especially in the USA, as a significant barrier to high-quality care for EGs (Hawthorne and Tomlinson, 1999; Cone et al, 2003; Mainous et al, 2006).

In the present pilot study, the major cultural issues listed by practices included language barriers, misconceptions and misunderstanding about diabetes, low literacy rate, poor understanding of how the human body functions, lack of confidence with medications, lack of adherence with

medications, high “do not attend” rates for clinics, and poor diet control.

These findings support previous studies that found cultural differences in language, faith, traditional beliefs and lifestyle (Cone et al, 2003; Mainous et al, 2006). The *Audit Commission Patient Survey* (Healthcare Commission, 2004) also highlighted significant gaps in patient knowledge, understanding and confidence in managing diabetes, which were substantially more pronounced for people from EGs than for the white population.

Patient services and policy

The national minimum gold standards for the management of diabetes are set out in the *National Service Framework (NSF) for Diabetes: Standards* (DH, 2001). Standard 3, for example, states that:

“All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process.”

To put this Standard into practice, people with diabetes need the knowledge, skills, and motivation to assess their risks, to understand what they will gain from changing their behaviour or lifestyle and to act on that understanding by engaging in appropriate behaviours. In effect, this Standard encourages partnership in decision-making between the individual and the service provider, hence the recommendations from the NICE (2003).

NICE (2003) recommends “structured education programmes” as key interventions, and specifies that these must be systematic, formal and structural and be made available to everyone with diabetes at the time of initial diagnosis, and then as required, based on formal and regular assessment of need.

NICE also clearly specifies that the education sessions should be accessible to all people with diabetes and should include cultural, ethnicity and geographical issues. People with diabetes need accurate and consistent information and training for the management of their condition from multidisciplinary healthcare professionals, to empower them by giving them the skills and knowledge to take control and integrate self-management into their daily lives. This should be conveyed to them in a medium that they understand. It is therefore important for healthcare professionals to work in partnership with one another to deliver a joined-up, integrated service, based around the needs of the individual (Diabetes UK, 2004).

Although all the practices in the present study had a practice protocol for diabetes care, there were disparities in diabetes care delivery, as each practice tended to design their diabetes services according to the resources available. For example, two practices had an insulin conversion service; no practice had a patient group education service, but one was intending to start one within a week. The other three practices expressed an interest in EG education services but would need additional resources, such as training, funding, support and space.

Two practices stated that they would consider running services for EGs with diabetes both as practice-based only and as a locality-based service. One practice said it would consider doing so as a practice-based service only; another practice said it would not

Page points

1. NICE (2003) recommends “structured education programmes” as key interventions; these must be systematic, formal and structural, and be made available to everyone with diabetes at the time of diagnosis, and then as required, based on need.
2. NICE also clearly specifies that the education sessions should be accessible to all people with diabetes and should include cultural, ethnicity and geographical issues.
3. Three practices expressed an interest in providing education services for EGs but would require extra resources to start these, such as training, funding, support and space.

Table 1. Number of staff speaking one or more south Asian languages.

Language	GP practice				Total
	A	B	C	D	
Punjabi	2	11	2	4	19
Hindi	0	1	0	4	5
Urdu	6	1	0	5	12
Gujarati	1	5	0	3	9
Bengali	0	0	0	2	2
Total	9	18	2	18	47

"To support effective diabetes commissioning, practices should record the ethnicity of all people with diabetes at practice level, and also report these data centrally. This would assist in the planning and commissioning of diabetes services locally as well as nationally."

Author

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consider doing so either as a practice-based or a locality-based service, but would rather do it on an individual basis, perhaps tailored to the individual's needs. EG attendance at clinic appointments was >50% in three practices and <50% in the other practice.

These findings show that although the practices work autonomously, they were all conscious of the need to deliver high-quality diabetes care (by employing staff who speak some EG languages, for example). Lack of resources and culturally sensitive awareness to meet these patients' needs was also identified.

To mitigate these issues, practices need to liaise with one another to share good practice. They also need to ensure that the NSF recommendations regarding diabetes structured and formal education programmes are implemented, either on a one-to-one or group basis. Where these services are not available within a practice, people from EGs with diabetes (especially those newly diagnosed) should be referred on elsewhere.

Limitations

Although this was a pilot survey with a small sample size (four of the 63 GP practices in Coventry), it is representative of the population under investigation. The fact that the questionnaire had mostly closed questions may not have given participants the opportunity to expand on their responses. However, this is the essence of quantitative studies, which aim to chart results rather than providing a deep understanding of the topic.

Practice managers were asked to complete the questionnaires; responses were therefore based on their perceptions of the service provided by their practice. Gaps were identified in certain questions, so the questionnaire will be refined before the main survey, to ensure that all areas are covered. All 63 GP practices in Coventry will subsequently be invited to complete one questionnaire each.

In addition, the investigator gave a presentation in three of the four practices before handing a questionnaire to the practice manager for completion, which may have

contributed to the 100% response rate. This has been one of the strengths of the exercise.

Conclusions

The prevalence of type 2 diabetes is set to continue to rise, especially in EGs, who are particularly susceptible. This is expected to place an ever-increasing burden on families and the healthcare system. Studies have shown that better education and information both for people with diabetes and for staff are pivotal in promoting high-quality diabetes care (National Resource Centre for Ethnic Minority Health and Scottish Diabetes Group, 2004; O'Neill, 2005). However, language barriers and associated cultural issues mean that people from EGs with diabetes have more problems managing their condition.

There was evidence of disparity in diabetes care service delivery among the four practices and the issues that staff face in dealing with cultural issues, including lack of resources. It is therefore important that NHS staff receive cultural competence training to ensure that diabetes care is provided in a culturally sensitive manner.

Employers should ensure that adequate resources are in place to support a streamlined service within their practices to minimise inappropriate referrals to secondary care. Establishing effective diabetes networks between practices to share good practice could be one way forward.

These recommendations will not only benefit people with diabetes, but will also improve job satisfaction among staff and ensure that the diverse needs of the UK population are met, as set out in both the NSF for diabetes and the NHS Constitution (DH, 2001; 2010).

To support effective diabetes commissioning, practices should record the ethnicity of all people with diabetes at practice level, and also report these data centrally. This would assist in the planning and commissioning of diabetes services locally as well as nationally. Those responsible for planning and delivering diabetes services should have policies that address the needs of EGs and the diverse communities across the UK. ■




Delivering diabetes care to ethnic minority groups: A pilot general practice survey


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Appendix 2: DEDICTED project launch invitation letter and programme

MEETING MASTERS
SEFTON HOUSE
BRIDLE ROAD
LIVERPOOL
L30 4UG

Invitation










Coventry Delivering Diabetes Care to Ethnic Minority Groups - Project Launch

WEDNESDAY 10TH MARCH 2010

Venue
ALLESLEY HOTEL
BIRMINGHAM ROAD
ALLESLEY VILLAGE
COVENTRY
CV5 9GP



Dear Colleague

It is a great pleasure to announce the launch of the Coventry Delivering Diabetes Care (DDC) Project. Exploring potential barriers and solutions to delivering quality diabetes care to people from ethnic minority groups (BMG). This launch meeting has been organised to seek your views on how best this project can work for you to benefit your patients.

The DDC project is funded by the West Midlands Strategic Health Authority as part of a research fellowship with Warwick Medical School. The project seeks to identify areas where BMG patients are struggling to manage their diabetes due to language problems or lack of understanding and find new ways for BMGs and NHS staff to work effectively together, to share knowledge and provide support.

This meeting, sponsored by an education grant from TAKEDA Pharmaceutical Limited, will include invited speakers from the DDC project, NHS, Warwick Medical School and Coventry community.

If you are a GP, health care commissioner, practice nurse, practice manager or deliver diabetes services to patients in Coventry and you would like to attend, please book your place as soon as possible. The meeting is free to attend but limited to 100 places on a first come first served basis.

Yours sincerely

Peter Zeh

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Speakers include:-

- Prof Sudesh Kumar - Professor of Medicine & Associate Dean, Warwick Medical School & Honorary Consultant Physician, UHCW NHS Trust
- Dr Jackie Sturt - Associate Professor in Social & Behavioural Sciences, Primary Care Research Group Lead, DDC Project Principal Supervisor, Warwick Medical School
- Dr Vinod Patel - Associate Clinical Professor (Reader) in Clinical Skills, Warwick Medical School & Consultant Physician, George Eliot Hospital, Nuneaton
- Dr Mukesh Mistry - GP with Specialist in Diabetes, Paradise Medical Centre, Coventry
- Dr Kumkum Mishra - GP, Edgwick Medical Centre, Coventry
- Mrs Lyn Rowstron - Practice Manager, Walsgrave Health Centre, Coventry
- Peter Zeh - SHA Research Fellow & DDC Project Principal Investigator
- Mrs Harjeet Kaur Ghataurhae - Patient Representative
- Mr Inderjit Kumar - Patient Representative

COVENTRY DELIVERING DIABETES CARE TO ETHNIC MINORITY GROUPS

WEDNESDAY 10TH MARCH 2010

ALLESLEY HOTEL
ALLESLEY, COVENTRY, CV5 9GP

PROGRAMME

1230 REGISTRATION & BUFFET LUNCH

1330 CHAIRPERSON'S INTRODUCTION
Prof Sudesh Kumar

1345 DELIVERING DIABETES CARE PROJECT
- FINDINGS FROM THE GENERAL PRACTICE PILOT SURVEY
Peter Zeh

1410 A PERSONAL PERSPECTIVE OF LIVING WITH TYPE 2 DIABETES
Mrs Harjeet Kaur Ghataurhae & Mr Inderjit Kumar

1430 TREATMENT OF TYPE 2 DIABETES IN ETHNIC MINORITY PATIENTS
- PRIMARY CARE PERSPECTIVES
Dr Vinod Patel

1455 COFFEE BREAK & NETWORKING

1515 WORKSHOPS (Rotational, 30 minutes each)

WORKSHOP 1: COVENTRY DELIVERING DIABETES CARE PROJECT - EXPLORING POTENTIAL BARRIERS AND SOLUTIONS TO DELIVERING QUALITY DIABETES CARE TO PEOPLE FROM ETHNIC MINORITY GROUPS.

Dr Jackie Sturt, Prof Sudesh Kumar & Peter Zeh

WORKSHOP 2: HEALTHY LIFESTYLE ADVICE AND SCREENING

- GP FEEDBACK FROM PILOT TRIAL PRACTICE
Dr Mukesh Mistry, Dr Kumkum Mishra & Mrs Lyn Rowstron

1620 Q & A

Prof Sudesh Kumar, Dr Jackie Sturt, Dr Vinod Patel, Dr Mukesh Mistry, Dr Kumkum Mishra, Lyn Rowstron, Peter Zeh, Mrs Harjeet Kaur Ghataurhae & Mr Inderjit Kumar

1630 CLOSE

Prof Sudesh Kumar

Please register by returning the enclosed registration form Or contact Meeting Masters on
Tel: 0151 601 8470 Fax: 0151 601 8471 Email: registration@meeting-masters.co.uk

REPLY FORM

COVENTRY DELIVERING DIABETES CARE TO ETHNIC MINORITY GROUPS

WEDNESDAY 10TH MARCH 2010

ALLESLEY HOTEL
BIRMINGHAM ROAD, ALLESLEY VILLAGE, COVENTRY, CV5 9GP

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Special dietary/other requirements:

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NHS Trust

Warwick
Medical School

Appendix 3: The impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups: A systematic review

DIABETICMedicine

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Review Article

The impact of culturally competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups: a systematic review

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Accepted 26 April 2012

Abstract

Aim To examine the evidence on culturally competent interventions tailored to the needs of people with diabetes from ethnic minority groups.

Methods MEDLINE (NHS Evidence), CINAHL and reference lists of retrieved papers were searched from inception to September 2011; two National Health Service specialist libraries were also searched. Google, Cochrane and DARE databases were interrogated and experts consulted. Studies were included if they reported primary research on the impact of culturally competent interventions on outcome measures of any ethnic minority group with diabetes. Paper selection and appraisal were conducted independently by two reviewers. The heterogeneity of the studies required narrative analysis. A novel culturally competent assessment tool was used to systematically assess the cultural competency of each intervention.

Results Three hundred and twenty papers were retrieved and 11 included. Study designs varied with a diverse range of service providers. Of the interventions, 64% were found to be highly culturally competent (scoring 90–100%) and 36% moderately culturally competent (70–89%). Data were collected from 2616 participants on 22 patient-reported outcome measures. A consistent finding from 10 of the studies was that any structured intervention, tailored to ethnic minority groups by integrating elements of culture, language, religion and health literacy skills, produced a positive impact on a range of patient-important outcomes.

Conclusions Benefits in using culturally competent interventions with ethnic minority groups with diabetes were identified. The majority of interventions described as culturally competent were confirmed as so, when assessed using the culturally competent assessment tool. Further good quality research is required to determine effectiveness and cost-effectiveness of culturally competent interventions to influence diabetes service commissioners.

Diabet. Med. 29, 1237–1252 (2012)

Introduction

The burden of diabetes disproportionately falls on ethnic minority groups who recurrently experience higher morbidity and mortality than majority populations for complex cultural, physiological and linguistic reasons [1–4]. These groups do not always receive adequate diabetes care as a result of barriers such as linguistic difference, limited educational backgrounds and religious, health and illness beliefs that are not familiar to the majority population, thus predisposing them as vulnerable groups within their host country healthcare systems [5]. Some authors have argued that the provision of appropriate interventions by culturally and linguistically competent healthcare

professionals can confer important benefits, not only to people with diabetes and their families, but also to bring about cost savings in every nation's healthcare system [6].

Ethnic minority groups are defined as a population group with an ethnic origin different from that of the majority population of the host country [7,8]. Cultural competence in healthcare service delivery is present when

'individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions, and other diversity factors in a manner that recognizes, affirms, and values the worth of individuals, families, and communities and protects and preserves the dignity of each' [9].

For health interventions, defined broadly as care or services delivered to people in a research setting, to be culturally competent and successfully implemented by cultural groups,

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1237

healthcare workers need an awareness of cultural differences and are required to deliver healthcare services in an effective and compassionate manner, maximizing sensitivity and taking into account the patients' cultural beliefs, behaviours and needs [10]. This is because each culturally diverse group defines health and illness differently [11,12].

Five previous systematic reviews have focused on reviewing culturally competent education interventions in ethnic minority groups with diabetes and reported varied effects in health-related outcomes [13–17]. These reviews found that structured diabetes education programmes are central to effective diabetes self-management [15,16]. Culturally competent health education and case management models have some benefits over 'usual' care in improving glycaemic control and/or diabetes knowledge, but their long-term effects and sustainability on patient-centred and clinical outcomes are unknown [13,17]. Furthermore, another review suggested that diabetes self-management interventions effective in the general population, when modified to be culturally competent, can improve health-related outcomes in ethnic minority groups [14]. However, little is known about (1) which components and implementation process constitute a culturally competent intervention and (2) what is the impact of culturally competent interventions for ethnic minority populations with diabetes [16,17].

Methods

Eligibility

Studies were eligible for inclusion if they reported primary research on the impact of culturally competent interventions on any outcome measures to any ethnic minority population within a majority population globally with any type of diabetes. No publication date or language restrictions were employed. Studies that did not focus on an ethnic minority group within a majority population were excluded.

Search strategy

The search strategy (Table 1) aimed to identify all references to diabetes, cultural competence and ethnic minority groups. The following databases were used from inception to September 2011: CINAHL and MEDLINE (NHS Evidence). In addition, searches using Medical Subject Headings (MeSH) and keywords were conducted using: Cochrane and DARE databases, the two National Health Service (NHS) specialist libraries hosted at Warwick University for ethnicity and health (<http://www.library.nhs.uk/ethnicity>) and diabetes (<http://www.library.nhs.uk/diabetes>), including the Warwick Medical School Research Publications from 2004 to 2011 (<http://www2.warwick.ac.uk/fac/med/staffintranet/staffresources/researchpublications/&NoOfYears=5>). The reference lists of included studies and relevant review articles were screened for additional

Table 1 Search strategy

Search terms
Unless otherwise specified, search terms are free text terms; MeSH for Medical Subject Headings (CINAHL and MEDLINE medical index terms); exp = exploded MeSH; adj = adjacent; ti,ab = title, abstract; * = truncation
'Diabetes' search terms
exp DIABETES MELLITUS/ OR exp DIABETES MELLITUS, EXPERIMENTAL/ OR exp DIABETES MELLITUS, TYPE 2/; (diabet*2 adj2)ti,ab; NIDDMti,ab; T2DMti,ab; (generational AND diabetes*)ti,ab; (juvenile AND diabetes*)ti,ab; Diabetes*1adj1ti,ab; (Type AND 1 AND diabetes*)ti,ab; T1DM*ti,ab; IDDM*ti,ab; exp DIABETES MELLITUS/ OR exp DIABETES MELLITUS, TYPE 2/
'Cultural competence' search terms
culture*ti,ab; (cultural AND competent*)ti,ab; (language AND barrier*)ti,ab; exp COMMUNICATION BARRIERS/ OR exp INTERDISCIPLINARY COMMUNICATION/ OR exp NONVERBAL COMMUNICATION/ OR exp COMMUNICATION/; (NHS AND healthcare AND systems)ti,ab; (NHS AND health AND care AND systems)ti,ab; (delivery AND healthcare)ti,ab; exp HEALTH SERVICES ACCESSIBILITY/; exp CULTURAL DIVERSITY/ OR exp CULTURAL COMPETENCY/ OR exp HEALTH SERVICES ACCESSIBILITY/ OR exp NURSING STAFF/; (religious AND beliefs*)ti,ab; (cultural AND awareness*)ti,ab; (cultural AND characteristics*)ti,ab; multicultural*ti,ab; transcultural*ti,ab; crosscultural*ti,ab
'Population' search terms
gujerat*ti,ab; bengal*ti,ab; exp ASIA, WESTERN/; exp INDIA/; bangladesh*ti,ab; gujarat*ti,ab; palistan*ti,ab; (south*adj2 AND asian*)ti,ab; ((south*adj2 indian*)ti,ab; Punjab*ti,ab; Urdu*ti,ab; Hindi*ti,ab; Hindu*ti,ab; (African AD) Caribbean)ti,ab; (ethnic AND minorities)ti,ab; (ethnic AND minority AND groups)ti,ab; human*ti,ab

citations and Google Scholar searched for grey literature. Four UK-based experts were consulted: in diabetes and ethnic minority groups ($n = 1$), diabetes and cultural competence ($n = 2$), and cultural competences ($n = 1$) to identify additional studies, and Google hand searches for any relevant papers written by three of these experts.

Selection criteria

Abstracts were independently screened for eligibility by two reviewers and disagreements resolved through discussion and consensus or third opinion. Agreement level was calculated using Cohen's kappa to test the inter-coder reliability of this screening process. The PRISMA flow diagram (Fig. 1) shows the detailed results of the screening and selection process [18].

Assessment of culturally competent interventions

Literature searches and consultation with experts were undertaken to identify tools for assessing cultural competence of interventions, but no existing tools were identified. The model

for the 'Development of transcultural competence' of Papadopoulos *et al.* [19] was therefore used as a basis from which a tool was developed for testing the cultural competency of healthcare delivery interventions; this tool was called the culturally competent assessment tool (CCAT) (see also Supporting Information, Table S1). Ten culturally competent criteria were formulated to systematically determine cultural competence within our review interventions. The culturally competent assessment tool was piloted, then used to assess study inclusion. A standard was set stating that cultural competence is achieved when a score of $\geq 70\%$ is attained.

Data extraction and quality assessment of studies

Data extraction was piloted by PZ and amended in consultation with the research team. Data extraction included authors, year and country of publication, study aims, setting, intervention aims, number and ethnicity of participants, study methods, intervention components and delivery methods, comparison groups and outcome measures, notes and follow-up questions for the authors. Missing data were clarified with three authors. Included studies were quality assessed using Moher *et al.* [20] for experimental studies, Popay *et al.* [21] for the action research and qualitative studies and the *Critical Appraisal Skills Programme* [22] for retrospective studies. Individual quality

assessment tools enabled us to focus on the specific study designs appropriately.

Results

Available evidence

The searches identified 320 papers (Fig. 1). Fifty-seven potentially relevant abstracts were identified and the full paper obtained, all of which were in English. Eleven studies were included. The inter-coder reliability of the screening process was high (kappa score 0.93). Forty were excluded because they were not culturally competent interventions delivered to ethnic minority groups with diabetes. Following the third opinion, an additional six studies were excluded because they were not explicitly related to ethnic minority groups with diabetes or were not culturally competent or related to research. There was considerable heterogeneity among the included studies therefore a narrative synthesis of the evidence was undertaken.

Characteristics of studies

Of the 11 included studies (Table 2), there were five randomized controlled trials [23–27]; two qualitative action research

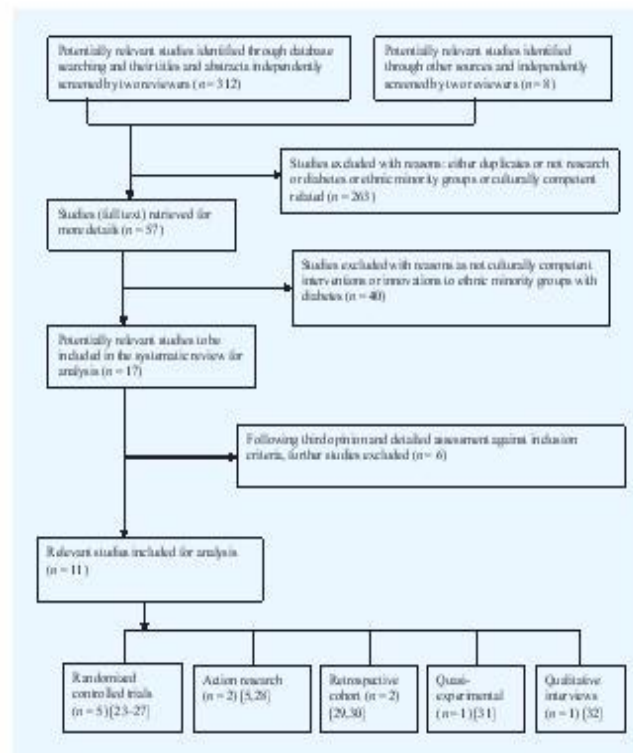


FIGURE 1 Flow chart (adapted from Moher *et al.*, 2009, PRISMA) [18] of screening and included studies.

studies [5,28] and two retrospective cohort studies [29,30]; one quasi-experimental design study [31]; and one qualitative study involving focus groups/interviews [32]. Studies were conducted in the UK ($n = 6$), the USA ($n = 3$), Denmark ($n = 1$) and Austria ($n = 1$). In total, 2616 participants were recruited: African-Americans ($n = 182$), African-Caribbean ($n = 22$), Asians ($n = 165$), Bangladeshis ($n = 42$), non-specified ethnic minority participants ($n = 37$), Hispanics ($n = 174$), Russians ($n = 55$), Turkish ($n = 39$), with South Asians ($n = 2000$) being the majority group studied from four UK-based randomized controlled trials. Nine studies included adults with Type 2 diabetes ($n = 2540$), one involved children with Type 1 diabetes ($n = 37$) [5] and another studied women with gestational diabetes ($n = 39$) [29].

Risk of bias

Three of the experimental studies were of 'A' quality [23,25,27], with the remainder [24,26,31] of 'B' quality using the criteria of Moher *et al.* (Table 3) [20]. All the trials clearly described withdrawal and dropout rates, including follow-up methodologies, and presented the interventions' outcome results. Three trials [23,25,27] included power calculations and these were greater than 80%. These studies also reported results by intention to treat. The flow of participants was not represented in a consort style diagram in two studies [26,31]. There were no allocation concealments of participants and intention-to-treat analyses were unclear in two randomized controlled trials [24,26]. All six studies were conducted in only two countries, the UK ($n = 4$) and the USA ($n = 2$). Overall quality assessment of the 11 studies found five of the studies to be good quality (scored A) [5,23,25,27,30], by meeting > 79% of the quality criteria, and six to be of moderate quality (B), meeting 50–79% of the quality criteria (see also Supporting Information, Tables S2 and S3).

Cultural competence of interventions

The culturally competent assessment tool was used to assess the interventions, which found 64% ($n = 7$) of the interventions to be highly culturally competent (scoring 90–100%). The remaining 36% ($n = 4$) were moderately culturally competent, scoring 70–89% (see also Supporting Information, Table S4). Five studies described their interventions as fully culturally competent [24,26,30–32], which was confirmed when the studies were assessed systematically using the culturally competent assessment tool.

Development and types of interventions

All 11 studies were complex interventions composed of components acting independently and/or interdependently [33]. Four interventions were one-to-one [23,25,29,30], four used group sessions only [24,27,28,32] and the other three applied both approaches [5,26,31].

Components and delivering of interventions

In two studies involving Bangladeshi subjects, pictorial material and videos were used for teaching/learning [27,28]. Two US studies with African-Americans successfully used financial incentives to recruit and retain participants [26,31]. Three of 11 studies [27,28,32] implemented informal learning methods amongst peers; however, in the one using unstructured learning, the primary outcome measures did not improve when compared with the control group [27].

The number and duration of intervention sessions varied. In the group education sessions, one intervention offered a 'one-off' session lasting 2.5 h [32], one implemented three sessions of 1–1.5 h per participant over 3 months [24] and two others offered fortnightly 2-h sessions over 6 months [27] and 10 formal programmes consisting of 3 h per participant over 12 weeks [28], respectively. Of the four interventions that provided individualized sessions, one provided extra nurse resources of 4 h per week [25], two provided unspecified weekly support of extra nurse resources [23] and dietitian/nurse educator resources [29], respectively. The other study undertook between one and six internal medication clinic visits annually [30]. The three studies [5,26,31], which used mixed delivery method approaches comprised of: one-to-one sessions of three meetings lasting 10–15 min per participant, along with the group sessions of 2 h weekly per group over 8 weeks [31]; one provided eight group meetings over 10 months and unspecified individualized sessions to four families, where an ethnic group could not be formed [5]; the other implemented either four intensive education sessions in groups or one-to-one, totalling 10–16 sessions per patient [26]. Apart from two studies [30,32], all the interventions clearly reported a follow-up period; the shortest was 10 weeks [31] and the longest was 2 years [25,26].

Nine interventions were delivered in primary and community care settings [5,23–28,30,31]. Of these, three were also delivered in hospital care settings (outpatient departments) [26,27,30]. Two studies [29,32] delivered their interventions exclusively in hospital settings. Three UK-based studies [23,25,32] used multilingual Asian link workers. Three interventions [26,30,31] had their providers from the same ethnic backgrounds as the participants. Two used bilingual health advocates to deliver their interventions [27,28]. The other three studies utilized providers with varied competences: two experienced bilingual health educators [24], an experienced nurse in diabetes and Muslim customs supported by interpreters [5] and a dietitian and nurse educator, supported by a translator [29]. The settings, service providers and model of delivering were similar in the two nurse-led interventions [23,25].

Training to deliver culturally competent interventions

Six studies explicitly described the diabetes cultural competence-related training of the interventionists, of which four comprised cultural competencies and/or standardized chronic

Table 2 Included studies

Study references (author and year)	Country/setting	Population	Participants in the intervention arm (n)	Participants in the control arm (n)	Comparison	Design	Mode and duration of intervention	Mode and duration of control	Delivery staff	Follow-up	Impact of intervention on outcomes
Garcia-Alhaja <i>et al.</i> , 2011 [27]	UK Primary and secondary	South Asians and Afro-Caribbean	79	78	—	Randomized controlled trial with in-depth process evaluation	Unstructured group sessions in groups of 10–12 participants, with sessions lasting for 2 h and held fortnightly over 6 months	Usual care structured diabetes education sessions in one group and one group by ethnicity groups led by a nurse and supported by an interpreter, if necessary	Trained bilingual health advocates in story-sharing models using an accredited curriculum over 12 weeks	12 months	HbA _{1c} P = 0.364 Total cholesterol Total/HDL P = 0.783 Systolic blood pressure, P = 0.123 Total well-being, P = 0.512. Patient involvement instrument (secondary outcome), P = 0.0002 Overall, no significant differences between intervention and control groups in biomedical outcomes, although attendance was 79% in intervention and 35% in control arms (P < 0.0001)

Table 2 (Continued)

Study references (author and year)	Country / setting	Population	Participants in the intervention arm (n)	Participants in the control arm (n)	Comparison	Design	Mode and duration of intervention	Mode and duration of control	Delivery staff	Follow-up	Impact of intervention on outcomes
Joshi <i>et al.</i> , 2010 [26]	USA Community and outpatient clinics	Hispanics and African-Americans	214 (110 African-Americans and 124 Hispanics)	100 (50 African-Americans and 50 Hispanics)	—	Randomized controlled trial	Four group classes or one-to-one culture-specific education sessions with diabetes educators from the same ethnic backgrounds as participants, including two weekly telephone follow-ups	Standard care (visit with a physician every 3–6 months)	Two trained nurse educators and two patients with diabetes (one from each group) who had completed a standardized chronic disease management training programme	2 years	HbA _{1c} : African-Americans— $P < 0.001$ Hispanics— $P = 0.004$ Lipids: African-Americans— $P = 0.064$ Hispanics— $P = 0.003$ Microalbuminuria: African-Americans— $P = 0.85$ Hispanics— $P = 0.85$ Emergency department visits: African-Americans— $P < 0.001$ Hispanics— $P = 0.001$ Hospitalization: African-Americans— $P = 0.010$ Hispanics— $P = 0.845$ Blood pressure: African-Americans—improvement Hispanics—no difference Eye checks: African-Americans—improvement Hispanics—not reported Weight: African-Americans—improvement Hispanics—improvement

Table 2 (Continued)

Study references (author and year)	Country/setting	Population	Participants in the intervention arm (n)	Participants in the control arm (n)	Comparison	Design	Mode and duration of intervention	Mode and duration of control	Delivery staff	Follow-up	Impact of intervention on outcomes
Bellary <i>et al.</i> , 2008 [25]	UK Primary care	South Asians	868	618	—	Randomized controlled trial	Culturally sensitive enhanced individual care package with 4 h per week of additional nurses' resources and prescribing algorithm	Standard routine care (using the same treatment protocols as intervention group)	Led by practice nurse with support from five trained multilingual workers	2 years	Main trial pressure — <i>P</i> = 0.018 Systolic blood pressure— <i>P</i> = 0.76 Diastolic blood pressure— <i>P</i> = 0.0001 Total cholesterol— <i>P</i> = 0.37 HbA _{1c} — <i>P</i> = 0.11 Coronary heart disease risk— <i>P</i> = 0.97 Weight circumference reduce— <i>P</i> = 0.67 BMB— <i>P</i> < 0.0001 Little financial impact (line of means) cost effectiveness ratio of £28 933 per quality-adjusted life year gained/£30 000 per quality-adjusted life year Knowledge— <i>P</i> = 0.27 Attitudes towards seriousness— <i>P</i> = 0.76 Attitude towards complications— <i>P</i> = 0.38 Perceived— <i>P</i> = 0.23
Baradaran <i>et al.</i> , 2006 [24]	UK Community and primary care	South Asians (Indians and Pakistanis)	59	59	27 white	Randomized controlled trial	Group diabetes education of between six and 12 participants, having three sessions with each lasting 1–1.5 h and completed within 3 months	Standard routine care	Two bilingual health educators (dietician and podiatrist)	6 months	

Table 2 (Continued)

Study references (author and year)	Country / setting	Population	Participants in the intervention arm (n)	Participants in the control arm (n)	Comp arm	Design	Mode and duration of intervention	Mode and duration of control	Delivery staff	Follow-up	Impact of intervention on outcomes
O'Hare et al., 2004 [13]	UK Primary care	South Asians	180	181	—	Randomized controlled trial	Enhanced individualized cultural sensitive care with additional nurses' resources per week and treatment algorithm	Standard routine care (using same treatment protocols as intervention group)	Led by practice nurse with support from two multi lingual Asian link workers, and community diabetes specialist nurse	1 year	Systolic blood pressure — $P = 0.015$ Diastolic blood pressure — $P = 0.003$ Total cholesterol — $P = 0.005$ HbA _{1c} — $P = 0.866$ Financial interest improved little improvement £1657/£264
Povlsen et al., 2005 [5]	Denmark Community	7 ethnic minority groups—65% Muslims	37 families	N/A	—	Action research	Development of an adapted and translated educational material and guidelines for healthcare professionals subsequent re-education of children with Type 1 diabetes and their families in seven groups of 4–6 or one-to-one based on age and ethnicity of the children. Sessions given in their parent's native language or Danish	N/A	Led by experienced nurse in diabetes care, immigration and Muslim customs and supported by interpreters and clinical dietitians	6 months	Educational material topic assessed with enthusiasm HbA _{1c} — $P = 0.01$, but increased after follow-up. Educational material and strategies —improvement Group attitude varied, with some liking group participation and others not. Knowledge of diabetes management —improvement; i.e. diabetes education improved diabetes knowledge level and led to short-term health benefits

Table 2 (Continued)

Study references (author and year)	Country/setting	Population	Participants in the intervention arm (n)	Participants in the control arm (n)	Design	Mode and duration of intervention	Mode and duration of control	Delivery staff	Follow-up	Impact of intervention on outcomes
Greshalgh <i>et al.</i> , 2005 [28]	UK Community	Bangladeshis	42	N/A	Action research using narrative methods	Diabetes support and education groups led by bilingual health advocates using 'story-telling' format in partnership with clinicians, managers, and service users. Ten formal programmes consisting of 3-h sessions undertaken over 12 weeks	N/A	Bilingual health advocates and researchers	18 months	Development of an intervention for diabetes education aimed to engage trained bilingual health advocates to facilitate narratives or story-telling approaches as part of a programme to improve diabetes management for neglected Bangladesh population. A user group led by bilingual health advocates successfully implemented, although not in all cases. Glucose concentrations of 'active participants' improved HbA _{1c} — $P = 0.007$ Lipid (LDL)— $P = 0.0002$ Systolic blood pressure— $P = 0.3$ Diastolic blood pressure— $P = 0.0002$
Mehler <i>et al.</i> , 2004 [30]	USA Community and outpatient department	Russians	55 (32 female and 23 male)	N/A	Retrospective cohort	Individualized care to assess outcomes pre-/post-arrival of a bilingual Russian internist. Cohort had between one and six internal medicine clinic visits annually	N/A	Trained bilingual Russian internist in language and culture concordance	1–6 clinics reviews per year	

Table 2 (Continued)

Study references (author and year)	Country/setting	Population	Participants in the intervention arm (n)	Participants in the control arm (n)	Comparison	Design	Mode and duration of intervention	Mode and duration of control	Delivery staff	Follow-up	Impact of intervention on outcomes
Hoppichler and Lechhammer, 2001 [29]	Austria Outpatient department	Mediterranean Turkish and Caucasian Austrian women with gestational diabetes	39 Mediterranean Turkish	N/A	72 Caucasian Austrian	Retrospective cohort	Individualized weekly gestational diabetes counselling, including dietary advice on food intake, insulin administration and techniques, signs and symptoms of hypoglycaemia and control procedures. Therapeutic regimen, including dietary recommendations and insulin therapy instructions, adapted to Turkish eating habits.	N/A	Led by a dietitian and nurse educator and supported by trained translators	Not clear	Thirty-one per cent of Turkish women (not pregnant) at initial visit found to be illiterate during intervention and a personalized education approach adopted with them. No significant differences in the clinical outcomes (family history of diabetes, HbA _{1c} , weight, etc.) except with eating habits as Mediterranean Turkish reported high intake of fat and carbohydrates, preferred female healthcare professionals and adherent to religious beliefs. Cultural appropriate care leading to similar clinical outcomes. HbA _{1c} , self-care actions, self-efficacy level, goal attainment and satisfaction with diabetes self-management education.
Uze et al., 2008 [31]	USA Community	African-Americans	22 (18 female and 4 male)	N/A	—	Quasi-experimental	Culturally tailored group vs. individual diabetes self-management education intervention to compare the impact				

Table 2 (Continued)

Study references (author and year)	Country/setting	Population	Participants in the intervention arm (<i>n</i>)	Participants in the control arm (<i>n</i>)	Consp articles	Design	Mode and duration of intervention	Mode and duration of control	Delivery staff	Follow-up	Impact of intervention on outcomes
Wilson <i>et al.</i> , 1993 [32]	UK Outpatient department	Asians	165 (96 male and 69 female)	N/A	—	Qualitative group discussions/ interview	Implementing a diabetes group education programme (one-off 2.5-h session in groups of 10–12 over 2 years) that promotes improvements in understanding and self-management for Asians with diabetes	N/A	led by two certified diabetes educators from the same ethnic backgrounds	10 weeks	HbA _{1c} , self-care activities and good attainment improved slightly in both groups over follow-up. Statistical trends indicated improved scores on dietary actions, foot care, goal attainment and empowerment in the group. Diabetes self-management education, but differences not statistically significant. Diabetes education programme for Asians was successful as it was tailored to their linguistic and cultural needs and improved their diabetes care. Two initial recruitments were poor and improved by Asian link worker making individual home visits. Public awareness of diabetes in the community improved by providing health education in social venues such as temple.

N/A, not available.

Table 3 Quality assessment for the experimental studies; randomized controlled trials + quasi experimental studies (adapted from Moher et al., 2010 [20])

Study references	Quality assessment criteria												%†
	1	2 (a + b)	3	4	5	6	7	8	9	10	11	12 (a + b + c)	
Greenhalgh et al. (2011)	Yes	Yes/no	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes/yes/yes	87% (A)
Joshi et al. (2010)	Yes	No/no	Yes	No	No	No	Yes	No	Yes	Can't tell	Yes	Yes/yes/yes	53% (B)
Bellary et al. (2008)	Yes	No/can't tell	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes/yes/yes	80% (A)
Baradaran et al. (2006)	Yes	No/can't tell	Yes	No	Yes	No	Yes	No	Yes	Can't tell	Yes	Yes/yes/yes	60% (B)
O'Hare et al. (2004)	Yes	No/can't tell	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes/yes/yes	80% (A)
Utz et al. (2008)	Yes	No/no	Yes	No	No	No	Yes	No	Yes	No	Yes	Yes/yes/yes	53% (B)

Questions relating to the quality criteria for assessment of the above experimental studies (adapted from Moher et al., 2010) [20]†

- 1 Is the study described as randomized and was the method appropriate?
- 2 (a) Were participants adequately blinded? (b) Was outcome assessment adequately blind?
- 3 Is there a description of withdrawals and dropouts and is this adequate?
- 4 Is allocation concealment described and was the method appropriate?
- 5 Is the flow of participants through each stage represented in a consort style diagram?
- 6 Did at least 80% of the number randomized provide data at the follow-up of interest?
- 7 Are clearly defined primary/secondary outcomes given?
- 8 Is there a calculation to determine the sample size described and was the method appropriate?
- 9 Is there a comparison of groups at baseline on demographic/clinical characteristics that may influence the effectiveness of the intervention, including outcome measures?
- 10 Is an explicit intention-to-treat analysis described?
- 11 Is an adequate summary of results for each outcome provided, including for non-significant results?
- 12 (a) Is the sample explicitly defined? (b) Is the method of recruitment adequately described? (c) Are precise details of the intervention/conditions for each group provided?

*Each of the 15 criteria answers 'yes' or 'no' or 'can't tell' and scores at least 8/15 (53%) in order for the study to be included.

†Scoring classification of the quality of included experimental studies:

—good quality studies must answer 'yes' to 80–100% of the quality assessment criteria and are scored as 'A';

—moderate quality studies must answer 'yes' to 50–79% of the quality assessment criteria and are scored as 'B';

—weak quality studies must answer 'yes' to less than 50% of the quality assessment criteria and are scored as 'C'.

disease management [25,26,31,32] and two were of cultural-competence training programmes and story-sharing models using an accredited curriculum over 12 weeks [27,28]. All 11 studies mentioned the qualifications of the service providers, which varied from primary education to degree level. In five studies, providers were certified to a minimum of registered nurse/dietitian level [5,24,26,29,31], and one was a medical doctor [30]. One intervention [5] was delivered by a nurse experienced in diabetes care, immigration and Muslim customs, with support from interpreters and clinical dietitians. The diabetes-related training in the link worker's study [23] was unclear. The link worker's roles were mainly limited to liaison and interpretations. The primary providers in three studies [5,23,29] appeared not to be linguistically competent by the use of interpreters/translators. Overall, the US studies provided greater details about the training of their interventionists. Nonetheless, eight studies reported successful use of locally available culturally appropriate media/communication tools, including the engagement of community or religious leaders to access participants to maintain motivation and including the use of delivery staff from the same ethnic backgrounds as participants [23,25,26,28,30–32].

Diabetes-related outcome measures

Across the 11 studies, 22 outcomes were reported including: 12 clinical, five psychosocial, three lifestyle and two healthcare utilization. Of these, five were objectively measured (e.g. HbA_{1c}), eight were self-report (e.g. satisfaction with care) and nine were measured by the research or clinical team (e.g. BMI). All but one study [27] reported at least two positive impacts on their participants diabetes-related outcomes.

Impact on clinical outcomes

HbA_{1c} was the main clinical outcome of interest and was reported in nine of the 11 included studies: Four of the randomized controlled trials evaluated HbA_{1c} changes [23,25–27], with only one [26] reporting statistically significant between-group changes in both Hispanics [decreased from 80 mmol/mol (9.5%) to 65 mmol/mol (8.1%), $P = 0.004$] and African-Americans [92 mmol/mol (10.6%) to 66 mmol/mol (8.2%), $P < 0.001$]. There were no improvements in HbA_{1c} in the other three randomized controlled trials. Four randomized controlled trials [23,25–27] also

evaluated total cholesterol levels and blood pressure. Statistically significant total cholesterol reduction in the intervention groups compared with controls were reported in two randomized controlled trials: at immediately post-intervention, there was an 18% ($P = 0.003$) reduction in the number of Hispanic participants with total cholesterol over 200 mg/dl [26]; and at 1 year a reduction of 0.4 mmol/L ($P = 0.005$) in the studied South Asian population [23]. The reduction in diastolic blood pressure was statistically significant in two randomized controlled trials [23,25] with changes in the intervention groups compared with controls lowered by 3.4 mmHg ($P = 0.003$) at the end of the 1-year period in one randomized controlled trial [23] and, after 2 years, a reduction of 1.6 mmHg ($P = 0.007$) in the other randomized controlled trial [25]. The only quasi-experimental study [31] found small HbA_{1c} improvement in both the group and individualized diabetes self-management. One of the two action research studies [5] measured HbA_{1c} changes, which decreased significantly immediately post-intervention [from 77 mmol/mol (9.2%) to 70 mmol/mol (8.6%), $P = 0.01$], when compared with baseline parameters, but was not sustained at the 6-month follow-up [increased to 76 mmol/mol (9.1%)]. The second action research study commented that glucose concentration of 'active participants' did improve [28]. Only one of the two retrospective cohort studies [30] reported statistically significant changes in HbA_{1c} [decreased from 68 mmol/mol (8.4%) to 64 mmol/mol (8.0%); $P = 0.007$]. No significant differences between the groups were reported by the other study [29].

Impact on knowledge, attitude change and self-efficacy

Only one of the randomized controlled trials [24] assessed diabetes knowledge, attitude towards seriousness/complications and self-care practices. Immediately post-intervention, the mean improvement changes between the ethnic intervention and control groups, respectively, were reported as: knowledge [1.72 (5.4), 0.47 (4.5); $P = 0.27$]; attitude towards seriousness [1.21 (2.4), 1.38 (2.2); $P = 0.76$]; self-care practice [1.02 (2.2), 0.26 (3.2); $P = 0.23$], showing no significant between-group differences. A qualitative study reported a small improvement in knowledge and attitude towards seriousness to diabetes care [5]. These authors, who report that the educational materials and topics were received with enthusiasm, although many of its topics were considered 'difficult' by participants, found that their intervention was successful in terms of participants citing what they had learnt from the education programme and how it met their needs. The quasi-experimental study [31] found an increase in change scores on measures of self-efficacy over the 10-week study duration in the intervention groups for participants receiving the group diabetes self-management education [+3.58 (5.43)] over individual diabetes self-management education, which were reduced [-1.13 (7.12); $P = 0.111$], although the reduction was not statistically sig-

nificant. A further qualitative study reported improvement in patient knowledge and outcomes [32]. In relation to health behaviour, one study [5] reported significant differences between the families associated with culture. The general attitude of participants varied, with some not liking to work with peers in groups and some who had to be provided with individualized education sessions, which had time and resources implications.

Evaluation of cost-effectiveness

Only one study formally assessed the cost-effectiveness of their intervention [25]. It analysed programme cost of £434 per patient over 2 years, and calculated cost in terms of quality-adjusted life year, which equated to an incremental cost-effectiveness ratio of £28 933 per quality-adjusted life year, gained compared well with the National Institute for Health and Clinical Excellence (NICE) suggestive norm of £30 000 per quality-adjusted life year [34]. The little cost savings were offset by increased consultation length of 4 h weekly of additional nurses' input. One of two studies estimated annual cost per patient at £365 compared with £264 for treating Type 2 diabetes [23], and the other estimated the cost of training a bilingual healthcare advocate or volunteer as group facilitator at £1500 and £345 to deliver the 12-week story-sharing course per patient [27].

Discussion

Statement of main findings

Our review found a small number of papers of heterogeneous research design. Ten of the 11 included studies reported at least two positive impacts on a wide range of patient-level diabetes outcomes. This success was found in the interventions that were structured, coupled with the fact that the service providers adapted teaching and learning methods that met cultural and community needs, fundamental to good care [17]. Whilst short-term improvements were observed in some studies in clinical and psychosocial outcomes, these changes were short-lived. There is some indication that knowledge improves as a result of culturally competent intervention. All studies were of moderate or good quality in relation to the characteristics of their particular design. South Asian communities were the focus of diabetes-related culturally competent intervention research in the UK and African-Americans in the US studies. These groups are the sizeable minority populations in many countries worldwide and are among the most susceptible to diabetes and related complications in both countries [16,35].

Strengths and limitations

The search criteria of this review included all ethnic minority groups with all types of diabetes and culturally competent

interventions globally. Interventions of any research design (from a wide range of sources including experts) that were culturally competent were assessed and included using the novel culturally competent assessment tool to ensure the inclusion of all relevant interventions previously undertaken in the area. Therefore, this design was robust because previous systematic reviews have limited their search to specific ethnic minority groups [14,15,36] or study types [13,17] or Type 2 diabetes [14,16,17] and have not formally assessed the level of cultural competence in interventions. The included 11 studies were assessed for both methodological quality and cultural competence. The review is limited by the different methodological studies. The lack of age restriction of participants posed a challenge in drawing of any conclusive views because of the heterogeneity of the populations. In addition, as only published studies were included, some relevant ongoing studies may have been excluded. The definitions of 'ethnic minority groups' and 'cultural competence' have been signposted in this review. However, these terms have been recognized as having no unique meanings [7,9].

The culturally competent assessment tool performed well as a tool to assess the cultural competence of the included studies. It was developed alongside the review and its content was informed by the contextual data surrounding the interventions under scrutiny. In this way the review informed the tool and may well account for its success in determining that the included studies were delivering interventions with a strong basis of cultural competence. The culturally competent assessment tool is not diabetes specific and theoretically could be used to assess the cultural competence of interventions aimed at any ethnic minority healthcare population. It could also be used to inform the development of a new culturally competent intervention and the next step in its development is to undertake some of this work to further test its validity and reliability. However, further empirical refinement of concepts within the culturally competent assessment tool is required.

Findings in relation to other studies

No specific trends were identified in terms of interventions that can produce notable improvements in HbA_{1c} in the South Asian populations. A previous review involving this population had suggested that trials of longer durations may have a significant improvement in glycaemic control in this group [16]. However, the two similar nurse-led interventions, which studied South Asians with 1 year of follow-up [23] and 2 years of follow-up [25], using 361 and 1486 participants, respectively, to evaluate HbA_{1c} changes produced similar outcomes. This may be explained by the use of the link worker model, which meant that communication between the patients and the primary providers was sometimes indirect. The two US studies [26,30] where communication was direct from primary providers produced statistically significant improvements in HbA_{1c}, albeit of limited duration. These two studies [26,30]

that reported the most statistically significant diabetes-related improvements used dual interventions settings (community and hospital). Their delivery providers were highly trained in diabetes management and belonged to the same ethnic minority groups as the participants, therefore they were linguistically and culturally competent. However, it would appear that the reported outcomes might have come from delivering the interventions over a longer period, because following the same procedure for a shorter period [31] only produced small benefits. This has been confirmed in other diabetes-related reviews, which recommended that results reported immediately following an intervention or those after a brief follow-up period have limited reliability for informing commissioning decisions [17,37].

Communication

Communication in relation to intervention delivery and the assessment of outcome may both impact on the findings of these studies. The results of this review showed that communications between service providers and participants in some interventions were indirect, necessitating the use of link workers or interpreters/translators. The evidence suggests that communication barriers may inhibit the uptake of the intervention and the use of psychosocial and knowledge assessment tools, which are essential in determining the effectiveness of diabetes-related interventions [15,38]. They argue that communication must not only be seen in terms of linguistic barriers, because our health-seeking behaviour is influenced by our cultural backgrounds, belief systems and identity, as well as our past experiences in our countries of origin. Translators/interpreters may not, in all cases, be able to understand the communications of some of the patients or their providers and the meaning of what would have been said will be misleading. As some participants were found to be illiterate in one study [29], the proposed remedy to this is the use of tools such as audio-video methods of delivery with South Asians [39,40].

Conclusion and recommendations for future research

The findings suggest a need for a robust research agenda on culturally competent interventions in diabetes care services. The presence of cultural-competency components in every health-care service intervention should be assessed to ensure it meets the needs of specific ethnic minority populations. The culturally competent assessment tool can be further evaluated and strengthened to inform this agenda. As not all the intervention providers had formal training in diabetes and cultural competence, the resource needed to ensure successful interventions is unclear. Therefore, further studies are needed to investigate if formal culturally competent training for diabetes service providers generally produces a positive effect in diabetes-related outcomes in ethnic minority populations. Limited evidence on cost-effectiveness is available and we recommend that cultur-

ally competent interventions should include cost-effectiveness evaluation in their designs at the outset. Such findings may then be used to inform future commissioning of diabetes services and buy-in by its commissioners [17]. Furthermore, culturally competent diabetes service interventions involving ethnic minority groups should be designed to evaluate the satisfaction levels of patients and service providers, which may improve patient concordance and providers' job satisfaction [3]. Healthcare organizations should have culturally competent staff and services, which should result in positive health outcomes to ethnic minority groups [41]. Whilst there are some benefits for ethnic minority groups to conserve their cultural identities within their host nations, service providers should learn and be aware of the cultural and linguistic needs of ethnic minority groups to ensure that their perceived healthcare needs are met in a sensitive manner. Ethnic minority groups should be encouraged and assisted by service providers towards community integration of their host nations. Although challenging, the pursuit for culturally competent healthcare systems in every nation requires further investigation to meet the increasing needs of ethnic minority groups [42].

Completing interests

Nothing to declare.

Acknowledgments

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Table S1. Culturally competent assessment tool for healthcare interventions in ethnic minority groups.

Table S2. Quality assessment for included qualitative and action research studies.

Table S3. Quality assessment for included retrospective cohort studies.

Table S4. Culturally competent assessment of included studies based on a novel devised tool titled: culturally competent assessment tool for healthcare interventions in ethnic minority groups by research authors.

Please note: Wiley-Blackwell are not responsible for the content or functionality of any supporting materials supplied by the authors. Any queries (other than for missing material) should be directed to the corresponding author for the article.

Appendix 4: Cultural barrier systematic review data extraction form

DATA EXTRACTION FORM – Cultural barriers (Revised Appendix 4)	
General Information	
Study number	
Study title	
First author	
Publication date (year)	
Country	
Reviewer initials	
Study details	
Acronym of study / common name	
Aim of study	
Specific study aim	
Participants	
Total no of participants & how they recruited	
Ethnicity and number or %	White Caucasian... African-Caribbean Indians... Pakistanis ... Bangladeshis.... Hispanics Other:
Interventions / Design	
Context of study setting (e.g. PC / OPD /community)	
Themes / Descriptions	Dietary intake <input type="checkbox"/> Literacy level <input type="checkbox"/> Language <input type="checkbox"/> Culture <input type="checkbox"/> Religion <input type="checkbox"/> Knowledge <input type="checkbox"/> Education <input type="checkbox"/> Other:
Methodological details	
Study type / design	Interviews <input type="checkbox"/> Case studies <input type="checkbox"/> Qualitative <input type="checkbox"/> Survey <input type="checkbox"/> Cohort <input type="checkbox"/> Before & After <input type="checkbox"/> Focus group <input type="checkbox"/> Other (please specify):
Data analysis method	
Content of cultural issues discussed	
Content of linguistic issues discussed	
Literacy level / rate	

Religion/health beliefs	
Other cultural issues discussed and impacts	
Can the findings be generalized or implement elsewhere in the data presented?	Yes <input type="checkbox"/> Partly <input type="checkbox"/> No <input type="checkbox"/> Missing elements?.....
Summary of key findings	
Conclusions	
Notes:	
Follow up questions for authors?	
<u>Purpose/query:</u>	<u>Outcome:</u>

Appendix 5: Culturally-competent care interventions data extraction form

DATA EXTRACTION FORM	
General Information	
Study number	
First 3 words of title	
First author	
Publication date (year)	
Country	
Reviewer initials	
Study details	
Acronym of trial / common name	
Aim of study	
Aim of intervention	
Participants	
Total no of participants at baseline	
Ethnicity and number or %	Caucasian Afro-Caribbean Indians... Pakistanis. Bangladeshis.... Hispanics..... Other: Asians ...
Interventions	
Context of intervention site (e.g. primary care /outpatients/community)	
Interventions Descriptions /	Dietary intake <input type="checkbox"/> Physical activity <input type="checkbox"/> Language <input type="checkbox"/> Education <input type="checkbox"/> Knowledge <input type="checkbox"/> Other:
Methodological details	
Study type	RCT <input type="checkbox"/> Case control <input type="checkbox"/> Qualitative <input type="checkbox"/> Observational <input type="checkbox"/> Cohort <input type="checkbox"/> Before and After <input type="checkbox"/> Other (please specify)
Allocation concealment	Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> If RCT
Randomisation	Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> If RCT
Blinding outcome assessors	Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> If RCT
Intention to treat analysis	Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> If RCT
Non-completers described	Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/>
MRC complex intervention framework phase and	

DEDICATED

evidence e.g. phase III: RCT with study power over 80%						
Content of intervention package (culturally competent element, how / who delivers it, what impact or effectiveness it has)	<u>Control:</u> If RCT <u>Intervention A:</u>					
Duration of interventions (Total time = no of sessions x length of time in mins)	<u>Control:</u> <u>Intervention A:</u> <u>Intervention B:</u>					
Delivery mode of intervention (single, group, family, non-participant partner)	<u>Control:</u> <u>Intervention A:</u> <u>Intervention B:</u>					
Programme type (information only, social skills)	<u>Control:</u> <u>Intervention A:</u> <u>Intervention B :</u>					
Delivery staff (GP, nurse, link worker, etc)	<u>Control</u> : N/A <u>Intervention A</u> : Asian linker worker & Diabetes Specialist Health Visitor <u>Intervention B</u> :					
Would it be possible to implement the intervention in a new clinical area from the data presented?	Yes <input type="checkbox"/> Partly <input type="checkbox"/> No <input type="checkbox"/> Missing elements?.....					
Results						
<u>Outcomes measured:</u> <u>(P) Primary</u> <u>(S) Secondary</u>	Significant (Y / N)		P-value	Improvement (I), decline (D) or no difference (ND) between groups	Data collection method	
e.g. Quality of life	Y		0.043	I	PAID questionnaire	
Education session attendance						
Longest follow-up selected						
Qualitative methods and results e.g. Focus groups with nurses (summarize headline findings)						

Notes / summary:	
Follow up questions for authors and others?	
<u>Purpose/questions:</u>	<u>Outcome:</u>

Appendix 6: National Research Ethics Service (NRES) ethical approval



**National Research Ethics Service
NRES Committee West Midlands - Solihull**

REC Office
Prospect House
Fishing Lane Road
Enfield
Boreham
B97 0EW

Tel: 01627 582534
Fax: 01627 582540

18 August 2011

Mr Peter Zeh
Strategic Health Authority PhD Research Fellow
University Hospitals Coventry & Warwickshire NHS Trust
Patient Research Interface Suite
2nd Floor, East Wing
University Hospital
Coventry
CV2 2DX

Dear Mr Zeh

Study title: Delivering Diabetes Care to Ethnic Diversity
(DEDICATED) in Coventry: Exploring potential barriers
and solutions to delivering quality diabetes care to
people from ethnic minority groups

REC reference: 11/WM/0218

Thank you for your letter of 28 July 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair and Committee members.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter	2.0	28 July 2011
Protocol		28 July 2011
Response to Request for Further Information		28 July 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review - guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:



National Research Ethics Service

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/WM/0218

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Timothy Priest
Vice Chair

Email: Karen.Green@westmidlands.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Dr Peter Hodges
Ms Louise Jones, West Midlands South Comprehensive Local
Research Network

Appendix 7: Letter to GP Surgery about the General Practice Survey

Delivering Diabetes Care to Ethnic Diversity (DEDICATED): Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

Dear Dr / Mr / Mrs / Miss-----

Thanking for taking time to read this letter. I am undertaking the above research study funded by NHS West Midlands as part of my PhD fellowship with Warwick Medical School, University of Warwick, which has received full Ethics Committee approval.

The aim of my study is to identify barriers to effective care delivery and the level of culturally-competent diabetes care services to patients with diabetes from ethnic minority groups (EMGs) in particular a target patient group of South Asian and African Caribbean origins. This may have potential to influence practice positively

I am aware that there are many areas of good practice across the general practice in Coventry, which provide patient centred diabetes care. This brief questionnaire will help us understand how local practices deliver diabetes services to patients from EMGs, what some of the challenges are and what additional resources are needed. I would be very much grateful if you could spend a few minutes completing the enclosed questionnaire and return it to me in the enclosed prepaid envelope. You can also complete it online if you prefer this method by accessing the following website:

Completing the questionnaire should not take you more than 25 minutes. We will pay your practice a sum of £40 if your completed questionnaire is received within 4 weeks from the date of this letter. If you return your questionnaire within 8 weeks, we will pay you £25. Please use the attached form to invoice Mrs Reena Savani Reena, Deputy Divisional Finance Manager, Research & Development, University Hospital, Coventry, CV2 2DX.

I am undertaking this study in collaboration with Warwick Medical School, NHS Coventry and UHCW NHS Trust who have advised me on all stages, including protocol development, design of the questionnaires and other areas.

All information you provide will be handled and treated in confidence and your name or that of your practice will not be made known to anyone other than the research team.

Thank you very much with your help with this research.

Sincerely yours

Peter Zeh
Strategic Health Authority PhD Research Fellow, DEDICATED CI, RGN
Patient Research Interface Suite (Opposite Ward 20), 2nd Floor East Wing
University Hospital, Coventry, CV2 2DX

Tel: 024 7696 5619 Email: peter.zeh@uhcw.nhs.uk

Request of payment for completed General Practice survey

Delivering Diabetes Care to Ethnic Diversity (DEDICATED) in Coventry: Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

**FAO Mrs Reena Savani
Deputy Divisional Finance Manager
Research & Development
1st Floor Rotunda
University Hospital, Coventry, CV2 2DX**

Dear Reena

I have completed a General Practice Questionnaire for the above study by **hard copy / online** on

(insert date) -----on behalf of (insert name of your practice) -----

which was sent by Peter Zeh on (insert date) -----

Please can you make the cheque payable to (insert payee details clearly):------

If you have any queries, please feel free to contact me.

Thank you for your cooperation in this matter.

Sincerely yours

Name of Practice Manager or designated staff: -----

Name and address of practice: -----

Contact telephone or email: -----

Signature of Practice Manager or designated staff: -----

Appendix 8: Invitation letter to case study practices for participatory research

Date: -----

Dear Dr:

Delivering Diabetes Care to Ethnic Diversity in Coventry: Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

Thanking for taking time to read this letter. I am undertaking the above research study funded by NHS West Midlands as part of my PhD fellowship with Warwick Medical School (WMS), University of Warwick, which has received full Ethics Committee approval.

The recent General Practice Survey shows that there is high number of ethnic minority groups (EMGs) with diabetes in your practice. The aim of our study is to identify how primary care teams can implement evidence based culturally-competent care services to improve diabetes outcomes for their ethnic minority patients. I therefore write to request if you would permit me to access your practice in order to observe interactions between EMGs and practice staff. This will be followed up with a discussion group and suggestions for service improvement, if appropriate.

We will pay your general practice £500 as appreciation for participating at the end of study. The enclosed Participant Information Sheet gives more details about the study and your surgery's involvement. Please can you read the information carefully and decide if you wish your surgery to participate.

I am undertaking this study in collaboration with WMS, Coventry PCT and UHCW NHS Trust who have advised me on all stages, including the development of the protocol.

If you are willing for your surgery to take part, please contact me by phone or email as below or reply using the slip below and return using the enclosed stamped envelope so that we can arrange to meet to discuss this further, should this be required. If you have any questions you would like to ask to help you decide whether or not your practice can take part in the research, please feel free to contact me.

I look forward to hearing from you soon and thanking you for your assistance in this matter.

Appendix 9: Invitation letter to staff participants about the PR meetings

Date: -----

Dear Mr /Mrs/ Ms / Miss/ Dr:

Delivering Diabetes Care to Ethnic Diversity (DEDICATED) in Coventry: Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

Thanking for taking time to read this letter. I am undertaking the above research study funded by NHS West Midlands as part of my PhD fellowship with Warwick Medical School (WMS), University of Warwick, which has received full Ethics Committee approval.

I am aware that there are many areas of good practice across Coventry general practices, which provides patient centred diabetes care. To help us understand how you deliver diabetes care to people from ethnic minority patients and also help commissioners to effectively design services locally, I write to invite you to take part in our discussion meetings over 7 to 9 months. Meetings will take place 3 weekly for no more than 90 minutes, totalling 11 to 13 meetings. The date and venue for the meetings will be defined around the needs and workload of your practice. The Lead GP within your practice will make the decision and you will be informed. Your participation in this study is voluntary and you may withdraw at any stage without giving reasons.

I am undertaking this study in collaboration with WMS, Coventry PCT and UHCW NHS Trust who have advised me on all stages, including the development of the protocol. The enclosed participant information sheet gives more details about the research. Please can you read the information carefully and decide if you wish to participate.

If you are willing to take part in the research, please contact me using my work phone number or email as below or reply using the slip below and return using the enclosed stamped envelope so that we can arrange a venue and time to discuss this further, if required. If you have any questions you would like to ask to help you decide whether or not to take part in the research, please feel free to contact me.

Peter Zeh

**Strategic Health Authority PhD Research Fellow, DEDICATED CI, RGN
Patient Research Interface Suite (Opposite Ward 20), 2nd Floor East Wing
University Hospital, Coventry, CV2 2DX**

Tel: 024 7696 5619 Email: peter.zeh@uhcw.nhs.uk

-----Please detach-----

My practice (Name): -----Is interested to take part in the research

Contact details of staff member: -----

Phone Number: -----

I agree to be contacted in relation to the research study described above and in the Participant Information Sheet.

Signed: ----- Dated: -----

Request of payment for participating in Implementation Research

Delivering Diabetes Care to Ethnic Diversity in Coventry: Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

**To Mrs Reena Savani
Deputy Divisional Finance Manager
Research & Development
1st Floor Rotunda
University Hospital, Coventry, CV2 2DX**

Dear Reena

The above study has successfully come to an end within my general practice (insert name of practice)

-----on (insert date) -----

I would be grateful if the payment of five hundred pounds (£500) can be made payable to (insert payee details clearly):

If you have any queries, please feel free to contact me.

Thank you for your cooperation in this matter.

Sincerely yours

Name of Lead GP or designated staff: -----

Name and address of practice: -----

Contact telephone or email: -----

Signature of Lead GP or designated staff: -----

I look forward to speaking to you soon and thanking you for your assistance in this research.

DEDICATED

Sincerely yours,

Peter Zeh

**Strategic Health Authority PhD Research Fellow, DEDICATED CI, RGN
Patient Research Interface Suite (Opposite Ward 20), 2nd Floor East Wing
University Hospital, Coventry, CV2 2DX**

Tel: 024 7696 5619 Email: peter.zeh@uhcw.nhs.uk

-----Please detach-----

Mr /Mrs / Ms / Miss / Dr: -----would like to participate in the DEDICATED discussion meetings

Address of General practice: -----

Contact telephone number: -----

I agree to be contacted in relation to the research study described above and in the Participant Information Sheet.

Signed: ----- Dated: -----

Appendix 10: Participant Information Sheet for staff taking part in the research

Research title

Delivering Diabetes Care to Ethnic Diversity in Coventry: Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

INFORMATION FOR STAFF PARTICIPANTS ABOUT THE STUDY

PART 1

1. An Invitation to participate

You are being invited to take part in the above research study funded by NHS West Midlands as part of a **research** fellowship with Warwick Medical School, University of Warwick. Whether you take part is entirely voluntary. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please carefully read the following information and feel free to ask us questions. Ask us if there is anything that is not clear or if you would like more information.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

2. What is the purpose of the study?

The aim of the study is to identify barriers to effective care delivery to patients with diabetes from ethnic minority groups in particular a target patient group of South Asian and African Caribbean origins. This may identify potential areas for improvement in practice.

3. Why have I been chosen?

You have been chosen because you are employed by a NHS organisation in Coventry or NHS Coventry and have been in your post for at least 6 months, providing diabetes services to ethnic minority people with diabetes or having commissioning responsibility of diabetes services in Coventry.

4. Do I have to take part?

No. Taking part in the study is entirely voluntary. It is up to you to decide whether or not to take part. You will be free to withdraw from the study at any time without giving a reason. You will be given up to three weeks to decide whether or not you would like to participate. Only when you are satisfied that you have been given enough information about the study and have decided that you would like to take part, you will be asked to sign the consent form attached on the first day of attending our implementation meetings or on the day of your interview (if you agree to take part in both). You will be given a copy of this information sheet and the signed informed consent **form** to keep.

If you decide to take part, you are still free to withdraw your consent to participate at any time and without giving a reason.

5. What will happen to me if I take part?

If you agree to take part, you would be invited to take part in the implementation or discussion meetings over 7 to 9 months. Meetings will take place 3 weekly for no more than 90 minutes, totalling 11 to 13 meetings. These meetings will include you, other staff members of your surgery, at least one patient from ethnic minority groups with diabetes and me or a member the research team. These meetings will be used to discuss suggestions for service improvement within your surgery, which may benefit your ethnic minority patients with diabetes. The suggestions for service improvement will be based on your **practice's** most cultural or linguistic barriers for EMGS from accessing effective diabetes care with the

practice. I will also share our findings from two systematic reviews on 'cultural barriers preventing EMGs from accessing effective diabetes care services and some of the interventions that have been successful around the world, if this is appropriate. The implementation meetings will take place at a convenient location decided by your Lead GP for diabetes, which may be within your practice building. These meetings will be audio-taped to aid transcription and analysis.

If you also agree to take part in a one-to-one interview with me or a member of the research team at the end of the implementation meetings, we would like to interview you about your experience for taking part in the implementation meetings, and the issues you face when delivering diabetes care services to people from **ethnic minority groups** and what you think can be implemented in your practice to improve your work and diabetes care to EMGs. If you have commissioning responsibilities, we would like to interview you about your perspectives of the planning and implementing diabetes services and the impact this has on addressing the needs of the local population. The interview may take up to one hour and will be conducted in private locations convenient to you. This would either be in your home or your office or the researcher's office at University Hospital, whichever, is convenient to you. The interview will be audiotape recorded with your permission, to aid transcription and analysis.

6. Will there be payment for taking part in the study?

Your General practice will be paid £500 for your participation and that of your colleagues at the end of the study. Your Lead GP for diabetes is aware of the minimum number of 5 – 8 participants we need for discussion / implementation meetings within your surgery. If we do not have the minimum number of participants at two consecutive meetings, we may not pay your surgery the full amount. However, this will be discussed with your Lead GP for diabetes in advance.

7. What are the possible disadvantages and risks of taking part?

The time given for the implementation meetings and/or one-to-one interview. You may be asked about your opinion about service improvements in the practice or about your experiences as a result of delivering diabetes care services to EMGs with diabetes. Your responses will be audio taped and you may say something that you may worry about later. At the end of every meeting or your one-to-one interview, I will check to see if you are happy for me to use the information you have provided.

8. What are the possible benefits of taking part in the study?

There are no immediate benefits from taking part. I hope that the information you provide may help improve the commissioning and delivery of diabetes care services to ethnic minority patients with diabetes. Practice may also change and designing of diabetes services may reflect the needs of the local population. However, no guarantees can be given that this will take place.

9. What if something goes wrong?

Any complaint about the way you have been dealt with during the study or any possible harm you might **have** suffered as a result of this study will be addressed. The detailed information on this is given in Part 2.

10. Will my taking part in the study be kept confidential?

Yes. All information about your participation in this study will be kept confidential. The details are included in Part 2.

11. Contact details:

If you require further information, please feel free to ask any questions you wish. Your

contact point for this study is:

Peter Zeh

DEDICATED Chief Investigator, RGN

Patient Research Interface Suite (Opposite Ward 20), 2nd Floor East Wing

University Hospital, Coventry, CV2 2DX

Tel: 024 7696 5619 Email: peter.zeh@uhcw.nhs.uk

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

PART 2

12. What will happen if I don't want to carry on with the study?

You are free to withdraw your consent to participate at any time and without giving a reason. You are also entitled to request if your past contributions in the implementation meetings should be included in the study or taken out and your decision will be respected. If you withdraw your consent at any point during the one-to-one interview, any data that has already been obtained from you will be destroyed in your presence and will not be included in the study.

13. Will my taking part in this study be kept confidential?

Yes. All information that is collected about you during the course of the research will be kept confidential under the Data Protection Act, 1998. Any audio-tapes of the implementation meetings or interview will be stored securely, and will not have your name on them. Transcripts of the implementation meetings or interview will not include any real names and we will change details that could be used to identify you. On completion of the research all material will be securely archived and later destroyed by Warwick Medical School.

The only time that confidentiality would be broken is if any serious professional misconduct is disclosed that indicates your patients' welfare is at risk. I would discuss this with you first. I would then seek advice from my supervisors who are also members of research team as to what further action (if any) needs to take place.

14. What if something goes wrong?

This is a non-invasive study. It is most unlikely that you will be caused problems by taking part in this research study. There are no special compensation arrangements. However, if you are harmed by someone's negligence, then you may have grounds for a legal claim. Also, if you wish to complain about any aspect of the way you have been approached or treated during the course of the study, you may speak to me or write to: Nicola Owen, Deputy Registrar, Deputy Registrar's Office, University of Warwick, Coventry, CV4 8UW or contact her on: Telephone: 024 7652 2785 or Email: Nicola.Owen@warwick.ac.uk and we will do our best to answer your questions. If you remain unhappy and wish to make a formal complaint, you can use the NHS complaints Procedure. Details can be obtained from the Deputy Registrar's Office or on the Internet.

15. What happens to the results of the research study?

The data from the implementation meetings and interviews will be analysed and the results written into a PhD thesis and research reports. This may have implications for service delivery, but this cannot be guaranteed. The results may also be published, but in any report or publication, we will not reveal your identity or that of your practice. If you would like a copy of the summary of the study findings, please indicate this on your consent form.

16. Who is funding this research?

NHS West Midlands has funded this research through a research fellowship with Warwick Medical School.

17. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed by NHS West Midlands, Warwick Diabetes Research and Education User Group, Warwick Medical School and the NRES Committee West Midlands - Solihull, who have raised no objection on ethical grounds.

If you wish to take part in the study, you will be asked to sign the consent form overleaf. A copy of your signed consent form and this information sheet will be given to you to keep.

Thank you for taking the time to read this information sheet.

Appendix 11: Invitation letter to patient about the implementation meetings

Date: -----

Dear Patient

Delivering Diabetes Care to Ethnic Diversity in Coventry: Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

Thanking for taking time to read this letter. I am undertaking the above research study funded by NHS West Midlands as part of my PhD fellowship with Warwick Medical School (WMS), University of Warwick, which has received full Ethics Committee approval.

I am aware that there are many areas of good practice across Coventry general practices, which provides patient centred diabetes care. To help us understand how you deliver diabetes care to people from ethnic minority patients and also help commissioners to effectively design services locally, I write to invite you to take part in our discussion meetings over 7 to 9 months. Meetings will take place 3 weekly for no more than 90 minutes, totalling 11 to 13 meetings. The date and venue for the meetings will be defined around the needs and workload of your practice. The Lead GP within your practice will make the decision and you will be informed. If you attend 75% or more of the meetings, you will give a £50 TESCO voucher as an appreciation for participating. Your participation in this study is entirely voluntary and you may withdraw at any stage without giving reasons.

I am undertaking this study in collaboration with Warwick Medical School, Coventry PCT and UHCW NHS Trust who have advised me on all stages, including the development of the protocol. The enclosed information sheet gives more details about the research. Please can you read the information carefully and decide if you wish to participate.

If you are willing to take part in the research, please contact me on my work telephone number or email detailed below or reply using the slip below and return using the enclosed stamped envelope so that we can arrange a venue and time to discuss this further, if required. If you have any questions you would like to ask to help you decide whether or not to take part in the research, please feel free to contact me.

I look forward to speaking to you soon and thanking you for your assistance in this research.

Sincerely yours,

Peter Zeh

**Strategic Health Authority PhD Research Fellow, DEDICATED CI, RGN
Patient Research Interface Suite (Opposite Ward 20), 2nd Floor East Wing
Tel: 024 7696 5619 Email: peter.zeh@uhcw.nhs.uk**

-----Please detach-----

Mr /Mrs / Ms / Miss / Dr: -----would like to participate in the DEDICATED discussion meetings

Address of General Practice: -----

Contact telephone number: -----

I agree to be contacted in relation to the research study described above and in the Participant Information Sheet. Signed: ----- Dated: -----

Appendix 12: Invitation letter about the study to ethnic minority patients to be sent out by GP surgery

RE:

Delivering Diabetes Care to Ethnic Diversity in Coventry: Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

Date: -----

Dear (Patient's name)

Peter Zeh is carrying out the above research study at Warwick Medical School, which has received full Ethics Committee approval and would like you to join our practice staff every 3 week for approximately 90 minutes to discuss how diabetes care services within our practice could be improved. The research will last 7 to 9 months, totalling 11 to 13 meetings.

At the end of the study, he may like to conduct a one-to-one interview with you to find out your experience for having and living with diabetes and what additional services you feel could be implemented within our practice to improve your diabetes care. He would like your help to assist him in the study and we have been asked by the NHS Coventry to contact you on his behalf.

Peter is doing this study in collaboration with Warwick Medical School, Coventry PCT and UHCW NHS Trust who are advising him on all stages of the study. We have enclosed a Participant Information sheet written by Peter, which explains the project in more detail.

If you agree to take part in the project, you will be asked to sign a consent form prior to your involvement.

If you feel that you would be willing to take part please complete the slip below and return it in the envelope provided or contact Peter Zeh directly via his details on the information sheet.

Taking part in the study is voluntary. Should you have any questions please contact your Practice Manager or Peter Zeh directly.

Yours sincerely

GP / Practice Manager

-----Please Detach-----

Mr/Mrs/Ms/Dr.....who has Diabetes Type 1 or 2 or gestational diabetes.....

Address:

Phone Number:

Appendix 13: Participant Information Sheet for patients taking part in the research

Research title

Delivering Diabetes Care to Ethnic Diversity in Coventry: Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

INFORMATION FOR PATIENT PARTICIPANTS ABOUT THE STUDY

PART 1

1. An Invitation to participate

You are being invited to take part in the above research study funded by NHS West Midlands as part of a fellowship with Warwick Medical School, University of Warwick. Whether you take part is entirely voluntary. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please carefully read the following information and feel free to discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

2. What is the purpose of the study?

The study aims to identify cultural barriers and solutions to effective care delivery to patients with diabetes from ethnic minority groups in particular a target patient group of South Asian and African Caribbean origins. This may identify potential areas for improvement in practice.

3. Why have I been chosen?

You have been chosen because you are aged over 18 and of either South Asian or African Caribbean origin living in Coventry and have diabetes.

4. Do I have to take part?

No. Taking part in the study is entirely voluntary. It is up to you to decide whether or not to take part. You will be free to withdraw from the study at any time without giving a reason. This will not affect the standard of care that you receive from any health care provider. You will be given up to three weeks to decide whether or not you would like to participate. Only when you are satisfied that you have been given enough information about the study and have decided that you would like to take part, you will be asked to sign the consent form attached on the first day of attending our discussion meetings or on the day of your interview (if you agree to take part in both). You will be given a copy of this information sheet and the signed informed consent form to keep.

If you decide to take part, you are still free to withdraw your consent to participate at any time and without giving a reason.

5. What will happen to me if I take part?

If you agree to take part, you will be invited to take part in discussion meetings over 7 to 9 months. Meetings will take place 3 weekly lasting no more than 90 minutes, totalling 11 to 13 meetings. These meetings will include you, staff members of your surgery and myself or a member the research team. These meetings will be used to discuss suggestions for service improvement within your practice, which may benefit ethnic minority patients with diabetes.

If you also agree to take part in a one-to-one interview with me or a member of the research team at the end of the discussion meetings, we would like to interview you about your experience of taking part in the discussion meetings and of having and living with diabetes

and what additional services you feel could be implemented in your practice to improve your diabetes care. The interview may take up to one hour and will be conducted in private locations convenient to you. This would either be in your home or your General Practice or Clinic Premises or your office, whichever, is convenient to you.

If you agree to take part in either or both activities, the discussion meetings and the one-to-one interview will be audiotape recorded with your permission, to aid transcription and analysis.

6. Will I be paid for taking part in the study?

You will receive a TESCO voucher of £50 as an appreciation for your participation at the end of the study. In addition, we will refund reasonable travel expenses you incur for attending our 3 weekly discussion meetings and/or your one-to-one interview visit, if the interview is not conducted in your home or office. Please note that we will require receipts in order to reimburse the amount.

7. What are the possible disadvantages and risks of taking part?

The time given for the discussion meetings and/or the one-to-one interview. You may be asked about your opinion about service improvements in your general practice or about your experiences as a result of having diabetes and the effects on you and your family. Your responses will be audio taped and you may say something that you may worry about later. At the end of every meeting or your one-to-one interview, I will check to see if you are happy for me to use the information you have provided.

8. What are the possible benefits of taking part in the study?

There are no immediate benefits from taking part. I hope that the information you provide may help improve the commissioning and delivery of care services to people in your similar circumstances. Practice may change and the designing of diabetes services may reflect the needs of the local population. However, no guarantees can be given that this will take place.

9. What if something goes wrong?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered as a result of this study will be addressed. The detailed information on this is given in Part 2.

10. Will my taking part in the study be kept confidential?

Yes. All information about your participation in this study will be kept confidential. The details are included in Part 2.

11. Contact details:

If you require further information, please feel free to ask any questions you wish. Your contact point for this study is:

Peter Zeh

Patient Research Interface Suite (Opposite Ward 20), 2nd Floor East Wing

University Hospital, Coventry, CV2 2DX

Tel: 024 7696 5619 Email: peter.zeh@uhcw.nhs.uk

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

PART 2

12. What will happen if I don't want to carry on with the study?

You are free to withdraw your consent to participate at any time and without giving a reason. This will not affect the standard of care you receive from any of your providers. You are entitled to request if your past contributions in the discussion meetings should be included in the study or taken out and your decision will be respected. If you withdraw your consent at any point during the one-to-one interview, any data that has already been **collected** from you will be destroyed in your presence and will not be included in the study.

13. Will my taking part in this study be kept confidential?

Yes. All information that is collected about you during the course of the research will be kept confidential under the Data Protection Act (1998). Any audio-tapes of the discussion meetings or interview will be stored securely, and will not have your name on them. Transcripts of the discussion meetings or interview will not include any real names and we will change details that could be used to identify you. On completion of the research all material will be securely archived and later destroyed by Warwick Medical School.

The only time that confidentiality would be broken is if you disclose information that indicates your welfare is seriously at risk. I would discuss this with you first. I would then seek advice from my supervisors who are also members of research team as to what further action (if any) needs to take place.

14. What if something goes wrong?

It is most unlikely that you will be caused problems by taking part in this research study. There are no special compensation arrangements. However, if you are harmed by someone's negligence, then you may have grounds for a legal claim. Also, if you wish to complain about any aspect of the way you have been approached or treated during the course of the study, you may speak to me or write to: Nicola Owen, Deputy Registrar, Deputy Registrar's Office, University of Warwick, Coventry, CV4 8UW or contact her on: Telephone: 024 7652 2785 or Email: Nicola.Owen@warwick.ac.uk and we will do our best to answer your questions. If you remain unhappy and wish to make a formal complaint, you can use the NHS complaints Procedure. Details can be obtained from the Deputy Registrar's Office or on the Internet.

For general advice and guidance for participants: Patient Advice and Liaison Service, PALS.

Local contact details can be found on <http://www.pals.nhs.uk> or contact them on 024 7624 6002 or Email: pals@coventrypct.nhs.uk and <http://www.pals.nhs.uk/> or Telephone: 0800 028 4203 or Email: PALS@uhcw.nhs.uk

15. Will my GP be informed?

With your permission, we will inform your GP about your participation in the study.

16. What happens to the results of the research study?

The discussion meetings and interviews will be analysed and the results written into a PhD thesis and research reports. This may have implications for service delivery, but this cannot be guaranteed. The results may also be published, but in any report or publication, we will not reveal your identity. If you would like a copy of the summary of the study findings, please indicate this on your consent form.

17. Who is funding this research?

NHS West Midlands has funded this research through a research fellowship with WMS.

18. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed by NHS West Midlands, Warwick Diabetes Research and Education User Group, Warwick Medical School and the NRES Committee West Midlands - Solihull, who have raised no objection on ethical grounds.

If you wish to take part in the study, you will be asked to sign the consent form overleaf. A copy of your signed consent form and this information sheet will be given to you to keep.

Thank you for taking the time to read this information sheet.

Appendix 14: Written contract between University of Warwick and participating practices

AGREEMENT FOR A PRACTICE IN A STUDY

SPONSORED BY UNIVERSITY OF WARWICK

This Agreement dated [Insert Date] is made between

University of Warwick, whose administrative offices are University House, Kirby Corner Road, Coventry CV4 8UW, ("the Sponsor")

AND

[add name of GP Practice], whose main administrative offices are [add address] ("Practice")

Hereinafter collectively, the "Parties", individually, a "Party"

This Agreement is made on the day of 20

BETWEEN

University of Warwick, whose administrative offices are at University House, Kirby Corner Road, Coventry, CV4 8UW (hereinafter referred to as University).

AND

[Name of GP Surgery] whose principal place of business is [add address] ("Practice").

WHEREAS

- A. The University has agreed to undertake the role of Sponsor, under the Department of Health Research Governance Framework for Health and Social Care, of a study entitled "Delivering Diabetes Care to Ethnic Diversity (DEDICATED)" (the "Study"), as described in the Protocol which forms Schedule 1 to this agreement ('Protocol').
- B. The Surgery wishes to take part in the Study and will fulfill their responsibilities as set out below and in Schedule 2.

The Parties agree to the following terms in respect of the clinical research study entitled "Delivering Diabetes Care to Ethnic Diversity (DEDICATED)" [ethics ref.: [Please insert ethics ref number]] (the "Study")

1. DEFINITIONS

The following words and phrases have the following meanings:

- 1.1 Sponsor - The individual, company, institution or organisation which takes responsibility for the initiation, management and/or financing of a clinical trial. For the purposes of this Study this shall mean The University of Warwick.
- 1.3 Chief Investigator (CI) – The person who takes overall responsibility for the design, conduct and reporting of the Study and who, for the purposes of this Study shall mean Mr Peter Zeh or a nominated successor.
- 1.4 Practice Lead - The individual taking responsibility for the conduct of the Study at the Practice.
- 1.5 Protocol - The description of the Study set out in Schedule 1 of this Agreement, and any amendments to such description that have been approved by a Research Ethics Committee having jurisdiction to give such approval.
- 1.6 Results - All discoveries, intellectual property, data, information, theories, methods, computer programmes, format of presentations and applications of the same and all manifestations or expressions of the same in physical, chemical, biological, molecular, electronic or written form, arising directly from the Study.
- 1.7 Participants – A person who consents to take part in the Study.

2. RESEARCH LAWS REGULATIONS AND CODES OF GOOD PRACTICE

- 2.1 The Parties agree to comply with any laws, regulations and codes of practice applicable to the performance of the Study including but not limited to the following: The Data Protection Act, 1998, 'The Declaration of Helsinki, 1996 titled "Ethical Principles for Medical Research Involving Human Subjects", The Freedom of Information Act, 2000, The Human Rights Act, 1998 and the relevant NHS Research Governance Framework for Health and Social Care
- 2.2 The references in Clause 2.1 shall be deemed to include references to any statute, subordinate legislation, declaration or framework which amends, extends, consolidates or replaces the legislation and the framework referenced in Clause 2.1
- 2.3 If the Sponsor's personnel attend or undertake any work at the Practice's premises the Practice shall notify the Sponsor's personnel of any Health and Safety policies as appropriate. The Sponsor shall comply, and shall ensure that its personnel comply with, the requirements of relevant Health and Safety policies as advised by the Practice.

3. OBLIGATIONS OF SPONSOR

- 3.1. The Sponsor shall take responsibility for Sponsor functions as set out in NHS Research Governance Framework for Health and Social Care.
- 3.2 The Sponsor shall use any data, or other information provided by or derived from a Participant and provided by or on behalf of the Practice to the Sponsor in accordance with the Participant's consent.

4. OBLIGATIONS OF THE PRACTICE

- 4.1 The Practice shall procure the services of **SITE PI** to act as Practice Lead.
- 4.2 The Practice shall ensure that the Practice Lead and his or her team are properly qualified trained and skilled to perform the procedures required by the Study and detailed in Schedule 2.
- 4.3 The Practice shall ensure that the Study and related activities at the Practice are carried out at all times in accordance with the current version of the Protocol.
- 4.4 The Practice shall ensure that the Practice Lead and their team comply with the requirements on the reporting of Serious Adverse Events and Serious Adverse Reactions described in the Protocol.
- 4.5 The Practice shall ensure that adequate facilities and support are available to the Practice Lead and its personnel for the proper performance of the Study at the Practice.
- 4.6 The Practice shall ensure that no Participant shall be recruited into the Study at the Practice until the Practice is satisfied that all relevant regulatory and ethics committee approvals have been obtained.
- 4.7 The Practice warrants that it will inform the Sponsor immediately if informed consent is withdrawn by a Participant participating in the Study.

- 4.8 The Practice shall assist the Sponsor with any audits or monitoring if reasonably requested during normal office hours on reasonable notice.
- 4.9 The Practice agrees to use its reasonable endeavours to meet the Responsibilities set out in Schedule 2.

5. LIABILITIES, INDEMNITY AND INSURANCE

- 5.1 Subject to Clauses 5.2 and 5.3 each Party indemnifies the other Party in respect of any loss, cost (including legal and other professional fees), damages, amounts paid in settlement of a claim or other financial liability suffered by one Party (the indemnified Party) as a result of any injury caused or alleged to be caused by the wilful act or negligence of an employee, agent or student of the indemnifying Party.
- 5.2 To the extent permitted by law, the liability of either Party to the other for any breach of this Agreement, for any negligence, or arising in any other way out of the subject-matter of this Agreement or the Study will not extend to any indirect or consequential losses.
- 5.3 The Practice warrants that it is and shall remain liable for the consequences of any failure on its part or on the part of the Practice Lead or its personnel, including its staff on honorary contracts and others engaged by it, to discharge the Study responsibilities in accordance with the terms of this Agreement.
- 5.4 The Sponsor shall indemnify the Practice against all claims arising out of the Sponsor's use of the Results of the Study.
- 5.5 The Practice warrants that it has appropriate insurance (including but not limited to Public Liability Insurance and Medical Indemnity Insurance) to cover its liabilities in respect of the Study and as set out in this Agreement. The Practice shall provide to the Sponsor such evidence of their individual insurance cover as the Sponsor shall from time to time reasonably request.

6. CONFIDENTIALITY

- 6.1 Medical confidentiality
 - 6.1.1 The Parties agree to adhere to the principles of medical confidentiality. Personal data shall not be disclosed to the Sponsor by the Collaborating Site save where this is required directly or indirectly to satisfy the requirements of the Protocol or for the purpose of monitoring or adverse event reporting and subject always to compliance with the Data Protection Act.
 - 6.1.2 The Sponsor shall not disclose the identity of Study Participants to third parties without the prior written consent of the Participant, in accordance with the requirements of the Data Protection Act 1998 and the principles set out in the Report of the Caldicott Committee on the review of patient identifiable information dated December 1997.
- 6.2 Confidential Information.
 - 6.2.1 In relation to Confidential Information received from one party to the other party, the parties agree to treat such Confidential Information in confidence and to use it only for the purposes of the Study, and to only disclose it to those persons who are required to know for the purposes of undertaking the Study or if required to be disclosed by law. For the avoidance of doubt,

intellectual property, data, personal data and know how shall be considered to be Confidential Information.

7. PUBLICATION

- 7.1 No Party shall use the name, logo or registered image of the other Party or their employees, consultants or agents in any publicity, advertising or press release without the prior written approval of an authorised representative of that Party.
- 7.2 Notwithstanding Clause 7.1, it is agreed that the Sponsor shall publish the results of the full Study and that the Practice and the Practice Lead shall not publish the results of the Study carried out at the Practice without the prior permission in writing of the Sponsor and in any case not prior to the publication of the results of the full Study.

8. INTELLECTUAL PROPERTY

- 8.1 All background intellectual property used in connection with the Study but not developed as part of it shall remain the property of the Party introducing the same.
- 8.2 All data, intellectual property rights and know how including the Results arising from the Study shall vest in or be exclusively licensed to the Sponsor and at the request and expense of the Sponsor, the Practice and the Practice Lead shall execute all such documents and do all such other acts and things as the Sponsor may reasonably require in order to vest fully and effectively all such data, intellectual property rights and know how in the Sponsor or its nominee.
- 8.3 Subject to Clause 6, the Sponsor hereby grants to the Practice a royalty-free, non-exclusive, non-transferable licence to use all intellectual property, data and know how assigned or licensed to the Sponsor by the Practice under this Clause 8 solely for non-commercial research and teaching purposes.

9. FINANCIAL ARRANGEMENTS

- 9.1 University Hospital Coventry and Warwickshire (UHCW) shall pay the Practice in accordance with the payment schedule as set out in Schedule 3. All payments made by the (UHCW) to the Practice under or in connection with this Agreement shall be deemed to be gross of any income tax liabilities and/or National Insurance, Value Added Tax or similar contributions.
- 9.2 The Parties agree that prior to payment the Practice shall submit an invoice in respect of its conduct of the Study setting out the payment claimed.

10. TERM

- 10.1 This Agreement shall commence on the date first written above and shall remain in effect until completion of the Study at the Practice and completion of the obligations of the Parties under this Agreement or until earlier termination in accordance with this Agreement.

11. TERMINATION

- 11.1 This Agreement may be terminated immediately by notice in writing:

- 11.1.1 without cause by the Practice provided that it shall ensure provision of appropriate follow-up for all Participants enrolled into the Study in accordance with the Protocol or, if appropriate, as required for safety monitoring purposes;
 - 11.1.2 by any Party if the other Party is in material or continuing breach of any of its obligations under this Agreement and fails to remedy the breach (if capable of remedy) for a period of 30 days after written notice by the non-breaching Party;
 - 11.1.3 by any Party if the regulatory permissions and approvals previously granted to perform the Study are withdrawn on grounds of Participant safety;
 - 11.1.4 by the Sponsor in the event that funding is withdrawn or terminated for any reason or there are insufficient funds available to continue the Study;
 - 11.1.5 by the Sponsor if the Practice is unable to fulfil the Responsibilities outlined in Schedule 2. Lead becomes unavailable to continue his/her supervision of the Study for any reason and an acceptable replacement is not found within a reasonable time taking account of the timeframe for the Study;
- 11.2 Any termination of this Agreement under this Clause 12 shall be without prejudice to any other rights or remedies of any Party under this Agreement or at law and will not affect any accrued rights or liabilities of any Party at the date of termination which shall survive the expiry or termination of this Agreement.

12. VARIATION

- 12.1 This Agreement and its Schedules (which are incorporated into and made a part of this Agreement) constitute the entire agreement between The Parties for the Study and no statements or representations made by either Party have been relied upon by the other in entering into this Agreement. Any variation shall be in 'writing and signed by authorised signatories for both Parties.

13. FORCE MAJEURE

- 13.1 No Party shall be liable for any delay in performance or failure to perform its obligations under this Agreement if such delay or failure is due to an occurrence beyond its control, provided that the Party in default notifies the other Party in writing of the reason for the delay or failure within 2 working days of such occurrence. If the delay continues for longer than 30 working days after such notification, or for longer than a total of 35 working days after the due date, the other Party shall be entitled to terminate this Agreement with immediate effect.

14. NOTICE

- 14.1 Any notice under this Agreement shall be in writing, signed by the relevant Party to the Agreement and delivered personally, by courier, by recorded delivery post; or by facsimile providing evidence of receipt, but not by e-mail.
- 14.2 Notices to the Sponsor shall be addressed to:

Director
Research Support Services
University House

DEDICATED

University of Warwick
Kirby Corner Road
Coventry CV4 8UW
Email: P.A.Hedges@warwick.ac.uk
Tel; +44 (0)24 765 23716
Fax: +44 (0)24 765 74458

14.3 Notices to the Practice shall be addressed to:

Notices Addressed to? – please add
Address – please add

16. DISPUTE RESOLUTION

16.1 In the event of a dispute the Parties agree to attempt to settle the dispute by mediation in accordance with the Centre for Effective Dispute Resolution Model Mediation Procedure. To initiate a mediation, a Party must give notice to the other Party requesting a mediation in accordance with this Clause. Any decision reached in this way shall be final and binding upon the Parties and any cost arising from the mediation shall be borne equally by the Parties or as directed by the mediator.

17. SURVIVAL OF CLAUSES

17.1 The following Clauses shall survive the termination or expiry of this Agreement: Clauses 1 (DEFINITIONS), 5 (LIABILITIES, INDEMNITIES AND INSURANCE), 6 (CONFIDENTIALITY) 7 (PUBLICATION), 8 (INTELLECTUAL PROPERTY) and 17 (SURVIVAL OF CLAUSES).

18. LAW AND JURISDICTION

18.1 This Agreement is made and shall be interpreted in accordance with the Laws of England and the Parties hereby submit to the exclusive jurisdiction of the Courts of England.

EXECUTION

Executed by The duly authorised representatives of the Parties on the date stated at the beginning of this Agreement

SIGNED ON BEHALF OF THE SPONSOR

Dr Peter Hedges.....Director Research Support
Services.....

Name
Date

Position

Signature

SIGNED ON BEHALF OF THE PRACTICE

DEDICATED

.....
Name Position Signature Date

READ AND ACKNOWLEDGED BY THE PRACTICE LEAD AT THE PRACTICE

.....
Name Position Signature Date

SCHEDULE 1 – Protocol

SCHEDULE 2

Practice Responsibilities

- To allow the Chief Investigator and/or a member of the DEDICATED team to observe interactions/clinical procedures between patients and staff, where the patient has consented to the same.
- Where appropriate to make patients aware of the Chief Investigator's and/or members of the DEDICATED team presence within the Practice.
- To ensure that only Practice Participants who have given their consent are included and take part in the Study.
- To ensure that those patients approached to take part in the Study are made aware of their rights to object to take part in the Study and/or their right to object to the presence of the Chief Investigator and/or a member of the DEDICATED team in their consultation with their clinician. **A NOTICE TO PATIENTS** (appendix 4.2.8A of page 38 of the protocol) will be displayed within the Practice and where applicable a copy shown to the patients.
- The Practice shall ensure between 5 to 8 participants (including at least 3 practice staff of which 2 must be clinical staff) will be present at the implementation meetings to be held every three weeks for at least one hour (approximately 11 – 14 meetings) over 7 – 9 months. Meeting dates and time will be agreed between Chief Investigator and Practice Lead and communicated to all Participants by the Chief Investigator in advance. The Practice shall be responsible for notifying Participants of any cancellation of the meetings.
- The Practice will inform the Chief Investigator at least 3 days in advance where Participants are unable to attend a meeting.
- The Practice shall recruit at least one expert patient (maximum of 2 patients) from their Practice, who will be made aware of the need to attend the implementation meetings that are held every three weeks for at least one hour (approximately 11 – 14 meetings) over 7 – 9 months..
- The Practice shall send out the assembled Invitation letters and patient information sheets provided by the Chief Investigator to potential patient Participants taking part in the implementation meetings. Stamps and envelopes will be provided by the CI.
- The Practice shall work with the Chief Investigator to implement where practically possible any actions arising from the implementation meetings, for a minimum trial period to be agreed with the Chief Investigator on a case by case basis.
- The Practice shall ensure that the Practice staff nominated to take part in the Study shall contribute to discussions during the meetings
- The Practice will provide a suitable venue within the Practice where the implementation meetings can take place.

SCHEDULE 3

FINANCIAL ARRANGEMENTS

The Sponsor will make payments as follows:

On completion of the Study the Practice should send an invoice for £500 to:

Mrs Reena Savani
Deputy Divisional Finance Manager
Research & Development
1st Floor Rotunda
University Hospital Coventry and Warwickshire
Coventry
CV2 2DX

Failure of the Practice to provide at least 3 Practice staff to take part in the implementation meetings for two consecutive meetings may lead to a reduction in the amount payable under this Agreement. However any such action will not be taken without the first notifying the Practice Lead.

Appendix 15: Patient Consent Form

Delivering Diabetes Care to Ethnic Diversity in Coventry: Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

Study Number: 11/WM/0218

Ethics Committee Approval Date: 16/08/2011.....

1. *	I confirm that I have read and understood the patient information sheet dated -----/----/----- (insert date of final REC approval version) for the above study and have had opportunity to ask questions.	<input type="checkbox"/>
2. *	I understand that I am being invited to take part in a research study. I understand the risks and benefits, and I freely give my informed consent to participate in the study described in this form, under the conditions stated in it.	<input type="checkbox"/>
3. *	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason and without my medical care or legal rights being affected.	<input type="checkbox"/>
4.	I understand that the Chief Investigator may look at my medical notes during this study. I give permission to him to have access to my records.	<input type="checkbox"/>
5. *	I give consent that my GP be notified of my participation in this study	<input type="checkbox"/>
6.	I give consent that a copy of my consent form to be placed in my health records with my GP, which would mean they would be aware of my participation in this study.	<input type="checkbox"/>
7.	I would like a summary copy of the study findings once the writing up of the study has ended. Please provide an address below.	<input type="checkbox"/>
8. *	I agree to take part in the above study.	<input type="checkbox"/>

Please put your initial in all boxes with asterisks in order to be eligible to enter the study. Any box without an asterisk is optional.

Please provide a phone number below in case I need to contact you during the study and a contact address or email if you want a summary of the study findings.

Tel: _____ Address: _____
Email: _____

Patient giving the informed consent to take part in the study:

Name: ----- Signature: ----- Date: -----Time: -----

Investigator, or another person delegated by the investigator, seeking informed consent

Name: ----- Signature: ----- Date: -----Time: -----

(Copies: 1 for patient; 1 (original for researcher); 1 to in medical record, if appropriate).

Appendix 16: Staff Consent Form

Delivering Diabetes Care to Ethnic Diversity in Coventry: Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

Study Number: 11/WM/0218

Ethics Committee Approval Date: 16/08/2011.....

1. *	I confirm that I have read and understood the participant information sheet dated -----/-----/----- (insert date of final REC approval version) for the above study and have had opportunity to ask questions.	<input type="text"/>
2. *	I understand that I am being invited to take part in a research study. I understand the risks and benefits, and I freely give my informed consent to participate in the study described in this form, under the conditions stated in it.	<input type="text"/>
3. *	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason and without my legal rights being affected.	<input type="text"/>
4. *	I consent to the disclosure of serious professional misconduct during the study period after full discussion with me.	<input type="text"/>
5.	I would like a summary copy of the study findings once the writing up of the study has ended. Please provide an address below.	<input type="text"/>
6. *	I agree to take part in the above study.	<input type="text"/>

Please put your initial in all boxes with asterisks in order to be eligible to enter the study. Any box without an asterisk is optional.

Please provide a phone number below in case I need to contact during the study and a contact address or email if you want a summary of the study findings.

Tel: _____ **Address:** _____
Email: _____

Staff giving the informed consent to take part in the study:

Name: ----- **Signature:** ----- **Date:** ----- **Time:** -----

Investigator, or another person delegated by the investigator, seeking informed consent

Name: ----- **Signature:** ----- **Date:** ----- **Time:** -----

(Copies: 1 for staff; 1 original for researcher).

Appendix 17: Notice Patients

Date: -----

Dear patients

RE: Delivering Diabetes Care to Ethnic Diversity (DEDICATED) in Coventry

Our practice is a teaching practice where trainees or researchers may attend your consultation.

Our practice is currently participating in the above study being undertaken by Peter Zeh. The study involves Peter observing interactions between you and us during your consultation. He may also take part in your consultation or in the delivering of your care.

Please let us know if you do not wish for this to happen in your case. We will respect your wish and this will not affect the level of care you receive with us.

If you wish to know more about this study, ask us and we will be happy to provide you with additional information.

Thank you for your patience.

Yours sincerely

GP / Practice Manager

Appendix 18: Topics for discussion at face-to-face interviews with ethnic minority patients

Delivering Diabetes Care to Ethnic Diversity (DEDICATED): Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

Firstly, just some practical questions about yourself?

- What is your name?
- What is your date of birth?
- What is your ethnic origin?
- What languages do you speak / understand and/or write?

About the 3 weekly implementation meetings you attended

- How would you describe your experience at the discussion meetings whether good or bad?
- How many sessions did you attend?
- Do you feel you were able to openly voice your own views and be heard, please elaborate on this?
- What was good about these meetings?
- When was your most frustrating moment, please elaborate?
- Do you think your contributions and suggestions and those of others will be taken into consideration to improve diabetes care for ethnic minority patients within the practice, why?

Now, questions on your diabetes and routine care

- Please tell me about your daily life with diabetes
- What type of diabetes do you have?
- When were you told that you have diabetes?
- How did you feel when you were first told that you have diabetes?
- How have you been managing since you were told you have this condition:
- For the first six months
- After six months?
- Were you told what kind of care or follow ups that you would be receiving?
- Have you had any of the following tested?
- your eyes
- your feet
- Your blood pressure
- And regular blood tests
- How regularly are these checks done and when was the last time?
- How has this impacted on your life, do you feel things have got better or worse since then?
- What has made the difference if any?

Barriers to care

- Which or what are the things (barriers) that stop you from receiving good diabetes care? Depending on aforementioned response, the researcher may explore further, e.g.
- Focusing on the cultural barriers, how do any of the barriers affect you on a daily basis and what, if anything do you think can be done to make things better for you?

Care providers

- Who (lay or professional) is involved in helping you with your diabetes care?

- Do you go to them or do they make home visits?
 - What other kind of support do you get to assist you to meet your cultural needs to improve your diabetes care?
 - Were you offered this support or did you have to ask?
 - What was recommended to you when you were first diagnosed with diabetes?
 - Has this happened?
 - Do you have named contact (s) for your diabetes care?
 - What other kind of support would you like?
 - Do you feel that you are aware of all the services that could be provided to you to help you with your care, for example do you feel that someone else is receiving other benefits to help them to meet their cultural or religious or language needs?
 - Are you aware of any diabetes education programmes?
 - Are you aware of the DESMOND programme and would you use it?
 - What about Apne Sehat Community interest Company?
- **Knowledge and awareness**
 - What education programmes for diabetes have you been offered or attended and do you feel that they were helpful in meeting your cultural needs?
 - Were you offered training to care for your diabetes and was it delivered appropriately?
 - Do you feel the training helped at all?
 - Were you satisfied with this training?

Being heard

- When you have a consultation with your GP, do you feel he/she listens to your concerns especially your cultural concerns?
- What about with other HCPs involved in their care; do you feel they listen to your concerns?
- How well do you think your GP or practice nurse is helping you to self manage your diabetes, do they teach you about the type of food, and other lifestyle habits that are common to your culture, please elaborate?
- Do they cooperate with you in collaboratively setting treatment goals?
- Do they dedicate time each time they are explaining your treatment or how to or take your medications or use your insulin pens?
- What is your message to HCPs involved in your care and other people like you?
- Do you feel that your diabetes has an impact on your relationships with your family and friends? Please elaborate on this.

Appendix 19: Draft topics for discussion at face-to-face interviews with general practice staff

Delivering Diabetes Care to Ethnic Diversity in Coventry: Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

Practical information

- Please can you confirm your name?
- The year you were born please
- What is your ethnic origin?
- What is your job title?
- How long have you been doing this job?
- What languages do you speak and understand?

Ethnic Minority Groups

- Do you encounter patients with diabetes from South Asian and African-Caribbean origins?
- What are the day-to-day issues that you face whilst providing diabetes care and services to these patients of South Asian and African-Caribbean origins?
- What do you understand by the term 'culturally competent'?
- (If unable to explain, researcher will explain) then, do you think this will help you to provide more appropriate care to EMGs?
- What culturally-competent practice have you found helpful in delivering diabetes care to EMGs with diabetes within your practice or elsewhere? Could you elaborate on this?
- From your perspective, what do you think their cultural needs (e.g. someone from India or Pakistan or Bangladesh, or African Caribbean) are?
- If so, how? If the answer is no, then expand on why not?
- How do you feel you take the patient's cultural needs and religious beliefs into consideration when providing diabetes care to them?
- Please expand further?

About the 3 weekly implementation meetings you attended

- How would you describe your experience at the implementation meetings good and bad?
- How many sessions did you attend?
- Do you feel you were able to openly voice your own views and being heard, please elaborate on this?
- What was good about these meetings?
- When was your most frustrating moment, please elaborate?
- Do you think your contributions and suggestions and those of others will be taken into consideration to improve diabetes care for ethnic minority patients within the practice, why?
- How you implement the suggestions/recommendations that we have developed to ensure they benefit EMGs within your practice?

Relationship with patients

- How would you describe your relationship with patients with diabetes from EMGs?
- What do you do when a patient from EMGs does not speak or understand English?
- What strategies do you employ to empower or help these EMGs patients to self manage their diabetes?
- Do you feel that these patients would benefit from culturally-competent education programmes, if so what types do you feel would be helpful?
- What is your attitude towards culturally-competent diabetes training? Have you had this training before and do you think it is important?

Training

- What other extra culturally-competent care services do you provide to diabetes patients from EMGs?
- Have you been formally trained to deliver this care or services to this group of patients?
- What did the training consist of?
- Is the training provided by a professional body and how effective do you feel it was?
- How often do you receive updates in diabetes care and who provides them?
- Are the updates structured and planned?
- Does the training actually help you to improve the care and services that you provide to the EMGs with diabetes?
- Do you think there is room for improvement for the quality of diabetes care you currently deliver to people from EMGs? How?
- What is the preferred training method that you think will ensure the delivery of high quality diabetes care for a culturally diversified community like Coventry?
- Do you feel culturally-competent training of staff will lead to improvements in diabetes related outcomes, including biomedical outcomes (e.g. HbA1C, BP, lipids) and patient reported outcomes quality of life in people with diabetes from South Asian or African Caribbean people including the other EMGs in Coventry? Please elaborate on this.
- Is there anything you would like to add?
- How do you feel about the ways diabetes services are commissioned in Coventry, do you feel there is room for improvement, how?

Appendix 19A: Topics for discussion at face-to-face interviews with staff

Delivering Diabetes Care to Ethnic Diversity (DEDICATED): Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

Practical information

- Please can you confirm your name?
- The year you were born please
- What is your ethnic origin?
- What is your job title?
- How long have you been doing this job?
- What languages do you speak and understand?

Ethnic Minority Groups

- Do you encounter patients with diabetes from South Asian and African-Caribbean origins?
- What are the day-to-day issues that you face whilst providing diabetes care and services to these patients of South Asian and African-Caribbean origins?
- What do you understand by the term 'culturally competent'?
- (If unable to explain, researcher will explain) then, do you think this will help you to provide more appropriate care to EMGs?
- What culturally-competent practice have you found helpful in delivering diabetes care to EMGs with diabetes within your practice or elsewhere? Could you elaborate on this?
- From your perspective, what do you think their cultural needs (e.g. someone from India or Pakistan or Bangladesh, or African Caribbean) are?
- If so, how? If the answer is no, then expand on why not?
- How do you feel you take the patient's cultural needs and religious beliefs into consideration when providing diabetes care services to them? Please expand further?

Role as Expert Patient Programme Worker (EPP) or Multilingual Link Worker (MLW) or clinical lead

- What are your roles or responsibilities as an EPP manager or MLW?
- What experiences and skills have you got to deliver this service?
- How would you like the diabetes services deliver to EMGs in Coventry and/or within your organisation?
- **(Depending on the response)**, how can you contribute to help bring about this?
- Can you give me a rough estimate of the total number of people with diabetes in Coventry?
- What types of diabetes services do you think are a priority for EMGs with diabetes in Coventry and/or within your organisation?
- What ethnic languages do you see as a priority for diabetes service redesign in Coventry and/or within your organisation?
- Can you tell me what you understand 'culturally-competent' to mean?
- Do you feel diabetes services are delivered to EMGs in Coventry and/or within your organisation take into consideration their specialised cultural and linguistic needs? Please elaborate on this.
- Are you aware of Diabetes NSF standards?
- What gaps do you see in the service delivery of diabetes care to EMGs with diabetes?
- If any, what are you doing about these gaps?
- Which would you prefer, the commissioning of diabetes care per head or per clinical need, and why?

Relationship with patients

- How would you describe your relationship with patients with diabetes from EMGs?

- What do you do when a patient from EMGs does not speak or understand English?
- What strategies do you employ to empower or help these ethnic minority patients to self-manage their diabetes?
- Do you feel that these patients would benefit from structured culturally-competent education programmes, if so what types do you feel would be helpful?
- What is your attitude towards culturally-competent diabetes training? Have you had this training before and do you think it is important? What did it involved?

Training

- What other extra culturally-competent care services do you provide to diabetes patients from EMGs?
- Have you been formally trained to deliver this care or services to this group of patients?
- What did the training consist of?
- Is the training provided by a professional body and how effective do you feel it was?
- How often do you receive updates in diabetes care and who provides them?
- Are the updates structured and planned?
- Does the training actually help you to improve the care services that you provide to the EMGs with diabetes?
- Do you think there is room for improvement for the quality of diabetes care you currently deliver to people from EMGs? How?
- **What is the preferred training method that you think will ensure the delivery of better diabetes care for a culturally diversified community like Coventry?**
- Do you feel culturally-competent training of staff will lead to improvements in diabetes related outcomes, including biomedical outcomes (e.g. HbA1C, BP, lipids) and patient reported outcomes quality of life in people with diabetes from South Asian or African Caribbean people including the other EMGs in Coventry? Please elaborate on this.

Update on study MLW framework model

- Is this something you would support and why/how?
 - Other MLW models have not fully delivered in the past because they serve mostly as liaison and interpretation, what training do you think MLWs should undertake in order to become Specialists and effective support EMGs with diabetes
 - What additional services can a specialist diabetes MLW offer?
 - Should a specialist MLW be a clinical person and what level of clinical qualification would you recommend?
 - This would be a new role, how can the SMLW work effectively with the MDT of professionals to ensure better diabetes care to the EMGs
-
- Is there anything you would like to add?
 - How do you feel about the ways diabetes services are commissioned in Coventry, do you feel there is room for improvement, how?
 - Is there anything you would like to say to the people from EMGs with diabetes living in Coventry?
 - Is there anything you would like to do differently to help the frontline staff to deliver culturally-competent diabetes care services to EMGs in Coventry?
 - Is there anything else you would like to add?

Appendix 20: DSMLW Job Description proposed by Admin Staff 1

Key Tasks

- To develop a working relationship with patients and practice staff as well as partner agencies. This may involve assisting qualified staff in appropriate domains within the practices and visiting ethnic minority patients in their homes or appropriate settings or contacting them by phone
- To signpost MLW model and support the ethnic minority patients in the practice and work towards their action plan as directed by clinical healthcare professionals
- To encourage the ethnic minority patients to take ownership of their diabetes action plan
- To arrange meetings and signpost community diabetes services to ethnic minority groups and support these networks (e.g. contacting service leads on behalf of the patient, training, etc)
- Work effectively in partnership with other general practices or agencies
- To keep clear and comprehensive records of work undertaken in accordance with local general practice and NHS Coventry record keeping protocol

Other Duties

- Undertake the mandatory induction training provided by the general practice and NHS Coventry.
- Undertake additional training as required by the employer.
- Maintain a professional relationship with patients at all times.
- Work positively in partnership with practice staff and partners and maintain regular contact with the Direct Line Manager and Clinical Leads in order to debrief, discuss issues and share relevant information.
- Undertake regular case management supervision with key workers.
- Abide by and be familiar with own Job Description and as required by employer.

These tasks may be carried out by individual multilingual link workers or working collaboratively with other multilingual link workers and practice staff. Working partnerships with patients may be from single meetings to several months, depending on the needs of the patient and as identified by healthcare professionals.

Multilingual Link Worker Person Specification

- Be at least 18 years old and of sufficient emotional maturity to take on a similar supportive role.
- Educated to NVQ Level 3 or diploma level (or its equivalent). Professional relevant health related field will be desirable
- Be committed to the multi-faith ethos of general practice and NHS Coventry.
- Be committed to the principles of diversity and equality.
- Experience of working with multi ethnic groups in clinical settings or similar settings.
- Be culturally-competent and able to communicate orally and in writing in at least one ethnic language, including English.
- Be able to work in a flexible, non-judgmental way.
- Be non-judgmental and respect every individual spirituality on its own terms, including those that do not have a religious connection.
- Have good interpersonal and communication skills.
- Be a good listener.
- Be able to work in a person centred way.
- Be well organised and resourceful.
- Be able to work in partnership with other members; staff, multilingual link workers and other agencies.
- Have basic IT skills.

Appendix 21: Generic Job Description for Multilingual Link Worker

Job Description

Job Title: Multicultural Diabetes Link Worker Programme (MDLWP) for Black and Minority Ethnic Communities

Responsible to: Multicultural Diabetes Link Worker Programme Manager

Hours of work: 0.5 whole time equivalent

Salary: Band 4 (Subject to Agenda for change banding)

Summary of role:

- To lead the work within the MDLWP on ensuring that the Programme is accessed by minority ethnic communities across the city and that it is sensitive to the needs of those communities.
- To support the MDLWP Manager in general promotion and implementation of the Programme.
- To ensure Diabetes education is delivered to agreed standard and regular monitoring is conducted e.g. onward referrals are completed, audits updates to team to meet agreed standards.
-

Main Duties:

1. Promote awareness and understanding of the MDLWP among all minority ethnic communities in the city.
2. Work with those communities to build confidence in the Programme and to enlist participants.
3. Devise flexible ways of delivering the Programme in community settings and with established minority ethnic groups.
4. To manage a caseload of clients to access follow on services; e.g. primary care services as appropriate
4. Ensure that all materials used for the Programme are accessible to people whose first language is not English and to people who do not read any language.
5. Encourage and support course participants who wish to become course tutors in order to ensure that the tutor group is representative of all communities in the city.
6. Work with other staff in the MDLWP team to ensure that general courses are accessible and welcoming to people from minority ethnic groups.
7. Liaise with regional and national MDLWP networks to share the learning from the work with minority communities in Coventry.

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8. Liaise with voluntary sector groups to ensure their full participation in the Programme.
9. Liaise with staff in the UHCW and other parts of the public sector to ensure that they are fully aware of the Programme and its particular relevance for people from minority ethnic groups.
10. Work with the MDLWP manager to develop Desmond and Daffani courses to complement the MDLWP and ensure that these achieve good uptake from minority ethnic communities.
11. Contribute to reports on the Programme for groups such as the Board, PEC and national bodies.
12. Ensure that learning from work with minority ethnic communities participating in the Programme informs work within the UHCW such as the Diabetes strategy.
13. Work as a member of the MDLWP team in the general promotion and implementation of the Programme.
14. Carry out other duties commensurate with the grade and purpose of the post.
15. Maintain confidentiality and ensure client data is kept in line with Data Protection Act.
16. To liaise with staff across organisations at various levels to set up screening sessions and offer support.

Corporate Responsibilities

1. To participate in the development review system, ensuring that planned objectives are achieved; to take responsibility for directing your own learning.
2. To ensure confidentiality of patient and staff information is maintained at all times.
3. To be familiar with and adhere to the Policies and Procedures of Coventry Teaching Primary Care Trust and the Corporate Services Department.
4. The Trust is an Equal Opportunities employer and the post holder is expected to promote this in all aspects of his/her work.
5. The post holder is an ambassador for the NHS UHCW. His/her actions and conduct will be judged by customers as an indication of the quality of the service provided by the Directorate and the UHCW as a whole.
6. To comply with the NHS Code of Conduct and any other Professional Code of Conduct relevant to the post.
7. To follow and adhere to the UHCW's Health and Safety Policies and instructions and be responsible for your own and others health and safety in the work place.
8. To ensure that all duties of this post are carried out so that they conform to good equal opportunities practice in line with the UHCW Equal Opportunity Policy and other

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related policies. The post holder should ensure their actions support equality and diversity at all times.

9. The legal requirements of the Sex Discrimination Act 1975 (as amended) Race Relations Act 1976 (as amended), the Disabled Persons (Employment) Act 1994 and 1998, the Disability Discrimination Act 1995 and all other Equalities legislation as it is enacted.

The Trust has a No Smoking Policy

This job description is an outline only and may be amended in detail and/or emphasis from time to time, to take account of any changes following discussion with the Post Holder.

Post Holders Name: _____

Manager's Name: _____

Post Holders signature: _____

Manager's Signature: _____

Date: _____

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Appendix 22: Request to PR group meeting participants to validate DSMLW Job Description

Patient Research Interface Suite,
3rd Floor Central (Opposite Ward 32)
University Hospital, Coventry, CV2 2DX

Date:.....

Dear [specify name of participant]

Delivering Diabetes Care to Ethnic Diversity (DEDICATED) in Coventry: Exploring potential barriers and solutions to delivering high quality diabetes care to people from ethnic minority groups

Thanking for taking time to read this letter.

Hope you are well.

I am sure you would have by now received the incentive payment that was promised to you for participating in the above study. Once again, I wish to thank you for giving your valuable time to participate in this study and for helping me achieved its objective.

During our fourth meeting held on 13 August 2013, one of our participants, [specify name of the participant], presented to us a draft of a Multilingual Link Worker Job Description. We further explored this Job Description in addition to the generic Multilingual Link Worker Job Description that was circulated by me. As assigned, I have put all the information together; please find enclosed a formulated draft of a proposed Job Description and person specifications.

Please can you kindly review the enclosed draft? You may make comments/amendments where applicable and return it back to me in the enclosed envelope within two weeks from the date of this letter. Please tick the appropriate box on page 2 to indicate your view regarding the job description and person specification. If you choose option 2, please provide your comments and continue overleaf, sign, and date page 2 and return it to me.

Following our work in designing this Diabetes Specialist Multilingual Link Worker (DSMLW) framework model for ethnic minority groups, I have had discussions with the Clinical Commissioning Group leaders, and they were generally happy with our work. Our next step is to prepare a Business Case for the service. Should this be successful, the enclosed Job Description will be used to advertise the post.

I look forward to hear from you soon.

Peter Zeh
DEDICATED Chief Investigator, RGN
Patient Research Interface Suite (Opposite Ward 32), 3rd Floor Central
University Hospital, Coventry, CV2 2DX
Tel: 024 7696 5619 Email: peter.zeh@uhcw.nhs.uk

Appendix 23: List of conference /seminar presentations arising from DEDICATED study so far (n=27)

Zeh, P., Sandhu, H. & Cannaby, AM & Sturt, J (2013) Designing effective culturally-competent diabetes care service in primary care: A participatory research study to implement evidence (**Poster discussion**), UK Society for Behavioural Medicine Annual Scientific Meeting, Oxford, 9-10 December 2013.

Zeh, P., Sandhu, H. & Cannaby, AM & Sturt, J (2013) How can we deliver diabetes care to ethnic minority populations - a single city case survey study (**Poster discussion**). International Diabetes Federation, Melbourne-Australia. 2-6 December 2013.

Zeh, P., Sandhu, H. & Cannaby, AM & Sturt, J (2013) Designing effective culturally-competent diabetes care service in primary care: A participatory research study to implement evidence (**Oral presentation**). The Chief Nursing Officer's BME Advisory Group 5th Annual Conference (Cultures of Compassion). University of Nottingham, 11 October 2013.

Zeh, P., Sandhu, H. & Cannaby, AM & Sturt, J (2013) A single city case survey on delivering diabetes care ethnic minority populations (**Poster presentation**), 2nd International Symposium on Advances in Human Metabolism Research, Translational Medicine, University of Warwick, 16-17 May 2013.

Zeh, P., Sandhu, H. & Cannaby, AM & Sturt, J (2013) A single city case survey on delivering diabetes care ethnic minority populations (**Poster presentation**), Diabetes UK conference, Manchester, 13-15 March 2013.

Zeh, P., Sandhu, H. & Cannaby, AM & Sturt, J (2012) A single city case survey: How do we deliver diabetes care to ethnic minority populations? (**Poster presentation**), Warwick Medical School Graduate Student Symposium, Warwick Medical School, 17 December 2012.

Zeh, P., Sandhu, H. & Cannaby, AM & Sturt, J (2012) A single city case survey: How do we deliver diabetes care to ethnic minority populations? (**Poster presentation**), South Asian Health Foundation (SAHF), Birmingham, 7-8 December 2012.

Zeh, P., Sandhu, H. & Cannaby, AM & Sturt, J (2012) A single city case survey: How do we deliver diabetes care to ethnic minority populations? (**Poster Presentation**), PCDS conference, Birmingham 16-17 November 2012. [Won the consolation prize].

Zeh, P., Sandhu, H. & Cannaby, AM & Sturt, J (2012) The provision of culturally-competent diversity interventions to ethnic minority groups with diabetes: A systematic review (**Poster Presentation**), Diabetes UK conference, Glasgow: 7-9 March 2012.

Zeh, P., Sandhu, H. & Cannaby, AM & Sturt, J (2011) A Systematic review of cultural barriers impeding ethnic minority groups from accessing effective diabetes care services (**Poster Presentation**), Diabetes UK conference, Glasgow: 7-9 march 2012.

Zeh, P., Sandhu, H. & Cannaby, AM & Sturt, J (2011) The provision of culturally-competent diversity interventions to ethnic minority groups with diabetes: A systematic review (**Poster Presentation**), 21st IDF Conference, Dubai: 4-8 December 2011.

Zeh, P., Sandhu, H. & Cannaby, AM & Sturt, J (2011) A Systematic review of cultural barriers impinging on ethnic minority groups from accessing effective diabetes care services (**Poster Presentation**), 21st IDF Conference, Dubai: 4-8 December 2011.

Zeh, P., Sandhu, H., Cannaby, AM & Sturt, J (2011) A Systematic review of cultural barriers impinging on ethnic minority groups from accessing effective diabetes care services, (**Poster presentation**), 7th National Conference of Primary Care Diabetes Society, NEC, Birmingham, 18-19/11/2011.

Zeh, P., Sandhu, H., Cannaby, AM & Sturt, J (2011) A Systematic review of cultural barriers impinging on ethnic minority groups from accessing effective diabetes care services, (**Poster presentation**), WMS 1st International Symposium on Advances in Human Metabolism Research, Warwick University, 11/11/2011.

Zeh, P., Sandhu, H., Cannaby, AM & Sturt, J (2011) A Systematic review of cultural barriers impinging on ethnic minority groups from accessing effective diabetes care services, (**Poster presentation**), 12th South Asian Health Foundation (SAHF) Annual Conference, NEC, UK, 07/10/2011.

Zeh, P., Sandhu, H. Cannaby, AM & Sturt, J (2011) Impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups: A systematic review (**Poster presentation**), 47th European Association for the Study of Diabetes (EASD) Annual Congress, Lisbon, 13/09/2011.

Zeh, P., Sandhu, H., Cannaby, AM & Sturt, J (2011) Impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups: A systematic review (**Oral presentation**), 2nd European Transcultural Nursing Association International Conference, Limerick University, Ireland, 30/06/2011.

Zeh, P., Sandhu, H., Cannaby, AM & Sturt, J (2011) Impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups: A systematic review (**Oral presentation**) International Conference on Making Diversity Interventions Count in Organisational Performance and Service Delivery, University of Bradford, 16/06/2011.

Zeh, P., Sandhu, H., Cannaby, AM & Sturt, J (2011) Impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups: A systematic review (**Oral presentation**), WISDEM Seminar Series, CSB, 27/05/2011.

Zeh, P., Sandhu, H., Cannaby, AM & Sturt, J (2011) Impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups: A systematic review (**Poster Exhibition**), UHCW NHS Trust, 17-18/05/2011.

Zeh, P., Sandhu, H. Cannaby, AM & Sturt, J (2011) Impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups: A systematic review (**PhD Poster Competition**), Warwick University, 13/05/2011.

Zeh, P., Sandhu, H., Cannaby, AM & Sturt, J (2011) Impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups: A systematic review (**Poster presentation**), Health Research at Warwick, Digital Lab, Warwick University, 05/04/2011.

Zeh, P., Sandhu, H., Cannaby, AM & Sturt, J (2011) Impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups: A systematic review (**Poster presentation**), Researching ethnicity conference, Manchester, 11/03/2011.

Zeh, P., Sandhu, H., Cannaby, AM & Sturt, J (2011) A systematic Review of the impact of culturally-competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups (**Poster presentation**). Annual WMS Research Student Symposium, 20/01/2011.

Peter Zeh, Harbinder Sandhu, Ann-Marie Cannaby & Jackie Sturt (2010) Delivering Diabetes Care to Ethnic Diversity (DEDICATED), NHS West Midlands NMAHP Research Training Celebration Event, (**Poster Presentation**) 30/04/2010.

Zeh, Peter (2010) Coventry Delivering Diabetes Care (DDC) to Ethnic Minority Groups: Findings from pilot general practice survey, (**Oral presentation**) Stakeholder event (DEDICATED project launch), Allesley Hotel Coventry, 10/03/2010.

Zeh, Peter & Sturt, Jackie (2010) Delivering Diabetes Care to Ethnic Diversity (DEDICATED) in Coventry: Project Launch – Stakeholders' event for Consultation, Allesley Hotel, Coventry, 10/03/2010.